REPORT ON PROCEEDINGS BEFORE

STANDING COMMITTEE ON LAW AND JUSTICE

PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

CORRECTED

At Jubilee Room, Parliament House, Sydney, on Monday 13 December 2021

The Committee met at 8:30 am

PRESENT

The Hon. Wes Fang (Chair)

The Hon. Anthony D'Adam
The Hon. Greg Donnelly (Deputy Chair)
The Hon. Scott Farlow
The Hon. Trevor Khan
The Hon. Rod Roberts

PRESENT VIA VIDEOCONFERENCE

The Hon. Taylor Martin

The CHAIR: Welcome to the third hearing of the inquiry into the provisions of the Voluntary Assisted Dying Bill 2021. Before I commence I acknowledge the Gadigal people, who are the traditional custodians of the land on which the Parliament sits. I would also like to pay respect to the Elders past, present and emerging of the Eora nation, and extend that respect to other Aboriginals present.

Today we will be hearing from NSW Health, in addition to representatives from other medical bodies, such as Palliative Care NSW, the Australian Medical Association (NSW) and the Royal Australian and New Zealand College of General Practitioners. We will also be hearing from a number of other medical professionals and academics in addition to groups representing the aged population. Before we commence I will make some brief comments about procedures for today's hearing. I note that the hearing room is closed to the general public today. This is due to room capacity restrictions under the New South Wales Parliament's COVID-safe arrangements. However, the hearing will be broadcast live on the Parliament's website.

While parliamentary privilege applies to what witnesses say giving evidence today, it does not apply to what witnesses may say outside of their evidence at the virtual hearing. I therefore urge witnesses to be careful about comments you may make to the media or others after you complete your evidence. Committee hearings are not intended to provide a forum for people to make adverse reflections about others under the protection of parliamentary privilege. In that regard, it is important that witnesses focus on the issues raised by the inquiry terms of reference and avoid naming individuals unnecessarily. All witnesses have a right to procedural fairness according to the procedural fairness resolution adopted by the House in 2018. There may be some questions that a witness could only answer if they had more time or with certain documents to hand. In these circumstances witnesses are advised that they can take a question on notice and provide an answer by 28 January 2022.

As I mentioned, today's proceedings are being live streamed. A transcript will be placed on the Committee's website when it becomes available. In terms of audibility for today's hearing, we have witnesses in person and via videoconference. I please ask Committee members to clearly identify who the questions are directed to and I ask everyone appearing remotely to please state their name their name when they begin speaking. Could everyone appearing via videoconference please mute their microphones when they are not speaking. Members and witnesses should avoid speaking over each other so that we can all be heard clearly. To assist Hansard, may I remind members and witnesses to speak directly into the microphone and avoid making comments when your head is turned away. I now welcome our first witness, Dr McMullen.

DANIELLE McMULLEN, President, Australian Medical Association (NSW), before the Committee via videoconference, affirmed and examined.

The CHAIR: Thank you very much, Dr McMullen. Would you like to start by making a short opening statement?

Dr McMULLEN: Thank you. I would also like to acknowledge the traditional owners of all the lands we are meeting on today and pay my respects to their Elders, past and present. The Australian Medical Association [AMA] thanks you for the opportunity to appear before this inquiry into the provisions of the Voluntary Assisted Dying Bill 2021. AMA NSW is the peak professional association representing all doctors in New South Wales across specialties and stages of career. Our overarching position is that voluntary assisted dying is a matter for society and government.

AMA NSW acknowledges that many jurisdictions in Australia and indeed around the world have enacted legislation for voluntary assisted dying. We see our role is to ensure that the medical profession is appropriately represented in the development of any legislation and to ensure that should New South Wales legislate voluntary assisted dying, then it is the most appropriate legislation. A number of our concerns were addressed in the process of amendments agreed to by the Legislative Assembly, namely, we are supportive of the removal of the requirement for doctors who are conscientious objectors to provide information to those seeking voluntary assisted dying and we are also pleased with the amendment related to the eligibility to act as a coordinating practitioner or consulting practitioner.

There do, however, remain a numbers of areas AMA NSW would like to raise as requiring closer attention. Firstly, in regards to the initiation by healthcare workers of discussions regarding voluntary assisted dying, we submit that clause 10 (3) should be removed from the bill as a discussion regarding voluntary assisted dying is not a discussion for an acute setting and is undertaken by a medical practitioner ideally as part of a considered discussion and as to treatment options of palliative care and voluntary assisted dying. In other jurisdictions healthcare workers, essentially other than doctors and nurse practitioners, are not permitted to initiate conversations about voluntary assisted dying.

Secondly, with regard to the time period between the first and final reports, we propose that the designated period in schedule 1 be extended to nine days to match that in other jurisdictions. There remains a provision in this bill for that period of time to be shortened if in the opinion of the coordinating practitioner and the consultant practitioner, the patient is likely to die or lose decision-making capacity in relation to voluntary assisted dying before the end of the designated period. We submit that the approach taken in Victoria and Western Australia is the preferred approach and the opinion of palliative practitioners that we have consulted is that nine days makes an accommodation for those patients who may suffer delirium or other short-term conditions that subside after a few days and may subtly affect decision-making capacity. Given there is a provision that allows for the time period to be shortened if death is imminent, there appears to be no persuasive reason for the shortened designated period.

Finally, with regards to the question of capacity, we question why the New South Wales bill has chosen to single out psychiatrists as health practitioners who may have appropriate skills and training to make such decisions. Other jurisdictions have not made such a stipulation. We encourage consultation with the Royal Australian and New Zealand College of Psychiatrists regarding the appropriateness or otherwise of specifically referencing referrals to psychiatrists. Of course, in closing, we would like to again call for improved funding and resourcing of palliative care in New South Wales. People with life-limiting conditions deserve comprehensive support and access to all information and options for their futures.

The CHAIR: Thank you very much. If you are happy, I will open up for questions now. I am just looking around the room. Are there any Committee members who have questions?

The Hon. GREG DONNELLY: Thank you for making yourself available this morning so early. In your opening statement you use a particular phrase, which you also specifically refer to in your submission in the introductory paragraph, at paragraph 1.2 of your submission at the end of the final sentence. I will not read it all but the second-last line states:

> … development of any legislation to ensure that, should NSW legislate on voluntary assisted dying, it is the most appropriate legislation.

My question to you, Dr McMullen, on behalf of the AMA NSW, whom you are representing today, is: What do you and the organisation mean by "most appropriate legislation"?

Dr McMULLEN: My understanding of our interpretation there is that it is legislation that is safe for both the doctors who are participating in the scheme and for patients of the scheme, accessible to patients requesting voluntary assisted dying and also acceptable to both doctors and patients trying to use the voluntary assisted dying scheme.

The Hon. GREG DONNELLY: So just going through your answer, it is safe for patients and doctors.

Dr McMULLEN: Yes.

The Hon. GREG DONNELLY: It is accessible, and what was the third element?

Dr McMULLEN: And acceptable.

The Hon. GREG DONNELLY: Acceptable to whom?

Dr McMULLEN: The doctors and patients so that both doctors trying to participate in the scheme, applying the restrictions around it, acceptable and implementable, and patients find that it is acceptable legislation to meet their needs. Predominantly, here we are representing doctors whose primary engagement in this process is from a doctor perspective to make sure that the legislation, if passed, is acceptable to the doctors trying to participate in it, that it is safe medico legally and professionally, and that it is implementable as well within our current medical framework.

The Hon. GREG DONNELLY: Just for clarity's sake, the AMA New South Wales branch, who you represent, do not have a policy position on assisted suicide and euthanasia?

Dr McMULLEN: Correct. We do default to the Federal AMA position but, as we have set out, the statement that AMA New South Wales has passed from our council is that we consider voluntary assisted dying to be a matter for society and government but, as was in my opening statement, that our role would be to make sure that doctors are adequately represented in the development of legislation.

The Hon. GREG DONNELLY: Could you please tell the Committee, either on notice or if you have got it with you, what is the AMA national body's position on assisted suicide and euthanasia?

Dr McMULLEN: We can provide that document on notice. It is not hugely lengthy but there is a document that provides the Federal AMA position so we could provide that on notice.

The Hon. GREG DONNELLY: And with respect to the World Medical Association—an organisation you would be well familiar with—do you know that organisation's position on assisted suicide and euthanasia?

Dr McMULLEN: I do not.

The Hon. GREG DONNELLY: You have never checked to see what that provision is, I guess? That is what you are saying—you are not familiar?

Dr McMULLEN: Personally I have not checked it ahead of this morning but again, if we want, I am sure we could find the document and provide it. It would be easily accessible.

The Hon. GREG DONNELLY: With respect to the World Health Organization as a global organisation, do you know its position with respect to assisted suicide and euthanasia?

Dr McMULLEN: I have not reviewed their position ahead of today.

The Hon. GREG DONNELLY: Okay, thank you. In terms of now looking at the bill itself, specifically—and thank you very much for elucidating on a few points and I will have to pass over shortly to colleagues—one of the issues in contest, if I could describe it this way, is around this theme of appropriate legislation. In at least Victoria, as an example, there is a provision requirement under the legislation, in terms of one of the two participating medically qualified people in the procedure dealing with the patient seeking assisted suicide potentially, for a specialist to be involved in that process.

Now that was placed in that legislation very explicitly and at the time in 2017 agreed in general that this was seen as a safeguard provision. If you review the *Hansard* debate in the Parliament in late 2017, which went over a period of time, it was all described as a safeguard by both sides—those pro and against assisted suicide and euthanasia—including quite esteemed medical organisations I have to say. Why would it be a position now that the requirement to have a specialist participating in this procedure, which is obviously a very significant procedure with a finality to it, that is either the person either is suiciding or—

The Hon. TREVOR KHAN: Greg, what is this with suicide today? The bill is the assisted dying bill and that has been the consistent term.

The CHAIR: Is there a point of order?

The Hon. TREVOR KHAN: Yes.

The Hon. GREG DONNELLY: Take the point of order.

The Hon. TREVOR KHAN: Point of order: As I have said, it seems to be an intent to now run a theme which is unnecessary in the terms of just getting to the facts of what this is about.

The Hon. GREG DONNELLY: To the point of order: The bill provides for providing an individual with the ability to commit suicide. We know this. That is what it provides for, or for an individual to be euthanised. That is what it provides for.

The Hon. TREVOR KHAN: It is actually a wrong terminology. It does not. Euthanasia does not involve a requirement for capacity.

The Hon. GREG DONNELLY: Well, I will go back to my—I could pull out the Oxford dictionary.

The CHAIR: Deputy Chair, I am happy to rule. Given that the bill—

The Hon. GREG DONNELLY: I have not even asked the question.

The CHAIR: Given that the bill is titled the Voluntary Assisted Dying Bill, I think it is an appropriate term to use, voluntary assisted dying. So I will uphold Mr Khan's point of order. If you are trying to describe other mechanisms, then you are in order. But, if you are referring to the bill and the provisions within the bill, I would ask you to adopt the terms within the long title of the bill.

The Hon. GREG DONNELLY: With respect to then at the time—which is not that long ago—the Victorian Parliament addressing this issue and seeing fit that a specialist be involved, and that was considered a significant and important part of safeguards, why is it the position now that it is no longer deemed to be a safeguard to involve a specialist and it is okay to have effectively two GPs, both of whom may have no relationship with the patient at all?

Dr McMULLEN: We did consider that change to the bill and whether we thought it was vital that one of the practitioners had specific specialty expertise in a condition of the person who is seeking voluntary assisted dying. We thought that other measures in this bill were strong enough—that is, that there is a strong obligation on both the coordinating and consulting practitioner to ensure that they do have adequate ability to make decisions about the condition that the patient has—that is, whether it is terminal within the next six months, or 12 months in the case of neurological condition—and we did not feel that there was a necessity for one of those practitioners to be of a particular specialty for that condition. The reason being that there is, as I said, that strong obligation for the practitioners to seek referral or other advice if they need more information and that our feedback from Victoria was that this does in some cases provide significant burden on a small number of practitioners, particularly for rare conditions, and also limits access potentially for people in regional and rural areas.

The Hon. SCOTT FARLOW: Thank you, Dr McMullen, for being here this morning. I just wanted to seek some elucidation from your submission with respect to eligibility requirements for practitioners. You state there that you have made representations and understand that amendments are to be made that address your concerns. If you could just outline those for the Committee, that would be helpful.

Dr McMULLEN: That was with regard to the eligibility requirements for practitioners. We had concerns with the initial draft of the bill that they included overseas-trained doctors who were under provisional registration here in New South Wales and that that placed an unnecessarily unfair burden on them and also their supervising practitioners. We thought it was just in its drafting there had been perhaps a misunderstanding of the medical system in that those practitioners would still be in some supervised practice and, as with the other categories of eligible practitioners, they are all more senior practitioners who have been practising in the New South Wales environment for some time. So we thought it appropriate that that group be removed, and our understanding is that they have been removed there.

The Hon. TAYLOR MARTIN: Funnily enough, my colleague just went to the same point I was about to make. Would you be able to just elucidate a bit more on the length of time that a doctor has been practising? Do you believe that the length of time as per the bill is long enough?

Dr McMULLEN: I think it is now—I am just trying to find that page in the bill, but my understanding is that it is now at 10 years. Correct me if I am wrong. We are happy with that.

The Hon. GREG DONNELLY: Just going back to your submission again—if I could just skip through these points—once again thank you for it. The matter of a person and their state of mind, if I could use that phrase—it is a generic phase, a layperson's phrase—towards the end of life with a condition that they have which is life limiting and also meeting the other criteria under the legislation under eligibility, we have had evidence from witnesses last Friday about the often circumstance where the person may find themselves depressed, actually clinically depressed, and obviously that is related to their circumstances.

The matter of that potentially not being diagnosed, that is, the person's clinical depression, and the impact that has on the decision-making, at least to me and I think others as well, seems to be of quite significant concern. Because it is probably understood that if the depression is diagnosed and treated, the person's state of mind may well change in terms of consideration of their circumstances. Why would the AMA not be ventilating issues around this matter of a person's state of mind, particularly around depression and related matters of circumstances, and therefore the need to be particularly careful that the person in fact is not depressed, or like or related conditions, and therefore that ought to be all taken into account before proceeding down the path of assisted suicide and euthanasia?

The Hon. TREVOR KHAN: Point of order: Again I take the point of order. Mr Chair, you ruled before and it happens again.

The CHAIR: I uphold the point of order.

The Hon. GREG DONNELLY: Or utilised in the provisions under the legislation.

The CHAIR: I make the point, so that we do not have to keep doing this all day, the Hon. Greg Donnelly was referring to the provisions of the bill. The bill is titled "Voluntary Assisted Dying". I would ask that the member refer to the acts under that provision by its correct term. I uphold the point of order from the Hon. Trevor Khan. Dr McMullen, are you able to provide a response to that?

Dr McMULLEN: Thank you. As has been said, this is about voluntary assisted dying. We would undertake that the requirement for two separate doctors to both consult with the patient about their reasoning, intent and illness and to discuss with them all options available to them for their care, including voluntary assisted dying, if a clinically significant depression that is likely to be affecting their mental state is apparent there, that that would be identified and diagnosed during that process. Because there is a requirement under the bill that patients need to be competent to be making such a decision, so part of that assessment of competence would be to be undertaking an assessment of the mental state in the clinical sense, the mental state of the patient in front of us and their ability to competently make that decision.

The Hon. GREG DONNELLY: If I can press this further, because there is still some time, am I right in hearing you just say—and I am quoting directly from you here, I think—that accessing voluntary assisted dying [VAD] under the legislation would be discussed potentially with the patient as an option for their care. That is the word you used, their "care". Is that the position of the AMA NSW?

Dr McMULLEN: We see voluntary assisted dying, if it is legislated that there is a role for doctors to have to participate in that, our view is that in general voluntary assisted dying is best discussed by patients who raise it in the course of them seeking information about what may happen to them at end of life. As we have discussed earlier, we do not see a role for healthcare workers other than doctors to be able to raise the issue of voluntary assisted dying, but we are certainly not advocating for doctors to always raise voluntary assisted dying. It is best done as part of a comprehensive discussion of end-of-life management. I hope that answers your question.

The Hon. GREG DONNELLY: No, it has not, because what you stated, Dr McMullen, was that in discussions with the patient it would be discussed in the context of an option for their care. That is what you said, on behalf of the AMA NSW. I am wanting to know, can you please explain how accessing VAD relates to the matter of providing care to the patient?

Dr McMULLEN: Let me clarify that should voluntary assisted dying be legislated, in general we expect that it will be raised by patients, by people who want to access voluntary assisted dying, ideally with their usual treating care team who understand all options of care for them. In that context, it can be discussed with them as an option for their end-of-life care management, should it be legislated in New South Wales.

The Hon. GREG DONNELLY: Could you just explain to me, with respect to a doctor having a patient in front of him or her and that patient's health was, let's use the vernacular, not in particularly good shape, they were dying; we are talking about a patient who had a condition that was terminal. In what circumstances would a doctor under your description raise with the patient the issue of voluntary assisted dying as an option?

Dr McMULLEN: Until this legislation is passed, we cannot answer that question. There are quite strict requirements under this proposed legislation about when and how that will be raised, and I think that is pretty clearly outlined in the draft legislation.

The Hon. GREG DONNELLY: Could you please explain to me how that is so? Based on the evidence you have just given a moment ago about the raising by the doctor with respect to the patient, you say there are restrictions around that. Can you explain where those restrictions are?

Dr McMULLEN: They are in the section about—

The Hon. GREG DONNELLY: Listen, this is not an ambush.

The CHAIR: Order!

The Hon. GREG DONNELLY: If you want to take it on notice—

Dr McMULLEN: —about initiating—

The Hon. GREG DONNELLY: I am sorry? If you need to take it on notice.

Dr McMULLEN: [Disorder].

The Hon. GREG DONNELLY: Sorry, I am just saying I am not trying to ambush you. If you do not know where the provisions are, you can take the question on notice. You appear to be suggesting that there are restrictions around the ability of a GP or members of your organisation to be able to raise with the patient the matter of, as you describe it, an end-of-life option, namely VAD. In other words, there is a restriction placed on the individual—

The CHAIR: I was listening intently to the answer and I believe Dr McMullen was referring to there currently being a restriction until the legislation is passed. Is that the correct interpretation of your answer just given before, Dr McMullen?

Dr McMULLEN: No, my answer was that even once the legislation passes and if it is passed in its current draft form, that there are some restrictions that doctors—the section we are referring to is 10 (2) where medical practitioners who initiate discussion make—there are a number of criteria set out there about what other circumstances must also be in place with a medical practitioner and what other information must be passed along for doctors to be able to initiate a discussion about voluntary assisted dying with their patients.

The Hon. GREG DONNELLY: So—

The CHAIR: Does the member mind if I pass to the Hon. Trevor Khan and then come back to you?

The Hon. GREG DONNELLY: Just if I am receiving the evidence correctly and then I will resubmit to the Chair.

The CHAIR: Sure.

The Hon. GREG DONNELLY: Obviously the heading of clause 10 in the legislation is, "Healthcare workers not to initiate discussion about voluntary assisted dying". Clause 10 (2) says:

> Subsection (1) does not apply to a medical practitioner—

I think that is the point you are making—

> who initiates a discussion or makes a suggestion …

And it continues:

> … the medical practitioner also informs the person about the following …

What this actually provides for, properly understood, Doctor, is not what you are saying at all. What it is saying is, if I read it correctly, if the medical practitioner raises those matters in a discussion—in other words, they initiate the discussion with the individual—meeting these matters you referred to in clause 10 (2) (a) to (d), they can raise the matter of this option you described earlier on as "care". Is that your understanding?

Dr McMULLEN: They can raise it if they meet those criteria and they have the professional ability to provide the answers and the information there outlined in 10 (2). But, yes, medical practitioners can raise voluntary assisted dying as an end-of-life option for patients if they are also able at that time to provide the detailed information outlined in 10 (2).

The Hon. TREVOR KHAN: Dr McMullen, if I take some of the evidence that we received correctly, particularly on Friday, some witnesses have proposed that there should be a requirement for the coordinating practitioner to communicate in some way with the treating general practitioner prior to proceeding under the provisions of the bill. If the treating general practitioner had refused to participate or had lost the confidence of the patient for some other reason, what would you envisage would be the nature of a discussion that would take place between the coordinating practitioner and the treating general practitioner?

Dr McMULLEN: As that is a matter we have not considered before, we can that question on notice and get back to you.

The Hon. TREVOR KHAN: Thank you. If you have a patient that says, "I want to do this range of care," whatever it be, "and I don't want you to speak to my former doctor." Are you in a position to, for instance, ignore the patient's request and then consult with the previous practitioner?

Dr McMULLEN: We can also get back to you on that one too.

The Hon. TREVOR KHAN: I would have thought that at the end of the day the patient wants to proceed on a particular course and you have undertaken an assessment of that patient and determined that they are capable and informed. You are not, as a general practitioner, entitled to go off on a jaunt of your own, contrary to what the patient has requested. That would be consistent with your ethical obligations, wouldn't it?

Dr McMULLEN: As I said, we can take the medico-legal matters there on notice and provide you a response with reference to the requirements under the bill for coordinating and consulting practitioners to have a full and complete picture of the patient's prognosis and ability to make decisions.

The Hon. TREVOR KHAN: Let me go one step further and say if a patient says to you, for instance, "I don't want you to tell a family member that I am undertaking a particular form of treatment," or, indeed, if this bill were to pass, to proceed with assisted dying, I would suggest to you that you are ethically bound to maintain the confidence of that patient. That would be correct, wouldn't it?

Dr McMULLEN: With that example of telling family members, correct, there are strict confidentiality requirements across all aspects of medical care and in general. If a patient has requested that you not share details of their medical treatment with a family member, then in general that is a wish that needs to be upheld.

The Hon. TREVOR KHAN: You would have seen in your own practice circumstances where the family members of a patient, particularly in the circumstance of a dying patient, can have a range of views as to treatment or what the patient should do in some form. That would be correct, wouldn't it?

Dr McMULLEN: That may be correct for some families.

The Hon. TREVOR KHAN: For instance, if a patient is in hospital, you might have a patient saying, "I want to go home to die." That may be a decision that is supported by some family members and vigorously opposed by other family members. That would be correct, wouldn't it?

Dr McMULLEN: It may be correct for some families, yes.

The Hon. TREVOR KHAN: In those circumstances, I suggest, patients will choose a course of action that may or may not be consistent with the views of part of the family, but that is the nature of life and families, is it not?

Dr McMULLEN: Correct.

The Hon. TREVOR KHAN: A suggestion that might be made from some of the evidence that the family should be informed of the patient's decision in a sense firstly invites a circumstance where the patient's desire for confidentiality would be breached by such an obligation, would it not?

Dr McMULLEN: We have not participated in that segment of giving of evidence, so I would not make a comment specifically on that.

The Hon. TREVOR KHAN: I think I am done because I am quite comfortable.

The Hon. GREG DONNELLY: Doctor, I am returning to the issue of clause 27 but also, earlier back, the issue of decision-making capacity. Do you think that generalists are qualified to make the necessary assessment regarding decision-making capacity and the matter of coercion? The evidence on Friday—and there has been evidence in submissions as well to this inquiry—was that the detection of coercion is most difficult. The actual detection of whether an individual has been coerced is most difficult and not something that can be quickly assessed. In other words, some of the evidence on Friday was that it takes, in fact, quite an astute and experienced individual—forgetting about medical qualifications for a moment—in detecting that a person has been coerced—coerced into anything, but this is obviously the matter of coerced into the possibility of voluntary assisted dying. Is it the evidence of yourself and the AMA that generalists—that is, the doctors that you represent—are qualified to be able to make this assessment about this matter of decision-making and whether or not coercion has taken or may be taking place?

Dr McMULLEN: We represent doctors across all specialties and would argue that doctors across a range of specialties may have the skills and expertise to undertake an assessment of decision-making capacity and the potential for coercion, and that depending on the specific patient circumstance and the questions around their capacity or around risk of coercion that that may be different specialties. For example, geriatricians are quite often involved in decision-making capacity assessments. Our main point around this was that by narrowing to psychiatrists, that may or may not give a representation that the whole specialty has specific expertise in decision-making capacity at the exclusion of other specialties, which we would say is not necessarily accurate. We have suggested consultations with that craft group to further define that and reassess whether that nomination of psychiatrists in these sections of the bill is necessary.

The Hon. GREG DONNELLY: That is not the question I actually asked. In answering the question, you are referring to a generalist who "may" have the skills in terms of the detection of coercion. I put this to you. What happens if a person with a life-ending illness happens to have a generalist doctor who does not have the skills, and that generalist doctor—picking up the point that you raised in my earlier line of questioning, if you have read the provisions of the legislation correctly, clause 10 (2)—as part of the care process, as you described it, raises the matter of assisted suicide and euthanasia, sorry, VAD, voluntary assisted dying, with the patient? Where does that leave the patient?

Dr McMULLEN: There is a requirement for doctors participating in the scheme to be able to be confident they have been able to assess the decision-making capacity of the patient and whether they are acting under duress or other influence. But if the generalist doctor did not have those skills, they would be required to highlight that and not participate in the scheme. It is, I put to you, equally likely that the patient may have a specialist doctor who does not have the requisite skills to assess decision-making capacity in that specific case. Decision-making capacity assessment is a complex assessment that varies depending on the matters that are up for question. So it is not limited to a specific specialty or indeed a non-GP versus a GP specialist as to whether they are able to participate in capacity assessments.

The Hon. GREG DONNELLY: Thank you, Doctor.

The CHAIR: Thank you, Dr McMullen. We are almost out of time, but before we leave you I wanted to quickly check, there has been debate this morning about the terms. For the layman, is suicide, euthanasia and voluntary assisted dying all considered three separate and different, discrete items by the medical specialties?

Dr McMULLEN: Certainly suicide without any qualifying factors would be considered different. We can get back to you on notice with what we would provide as our definitions where we see an overlap in terminology. But for the purposes of this bill, we have also been using "voluntary assisted dying" as the terminology throughout our communications with reference to this bill and what would be happening going forward in New South Wales.

The CHAIR: Thank you very much, Dr McMullen. We have come to the end of our time. If you have taken any questions on notice, we will be in contact with you about tabling your response. I thank you very much for making yourself available this morning. I know you have been very busy and we thank you for making yourself available.

(The witness withdrew.)

NIGEL LYONS, Deputy Secretary, Health System Strategy and Planning, NSW Health, sworn and examined

LEANNE O'SHANNESSY, Executive Director, Legal and Regulatory Services, General Counsel, NSW Health, sworn and examined

The CHAIR: I now welcome our witnesses from NSW Health. I remind witnesses and members that the Committee has resolved that Government representatives are expected to not take a position on the bill but they will need to provide factual information on matters such as current, legal and medical arrangements for those in care approaching end of life and how the provisions of the legislation might work should the legislation pass the Parliament. Would either or both of you like to start by making an opening statement?

Dr LYONS: We do not have an opening statement, Chair. We are happy to answer any questions the Committee might have.

The CHAIR: Thank you very much.

The Hon. ANTHONY D'ADAM: Thank you for your appearance today. I wanted to ask about the Health secretary's role under the proposed legislation. One of the consistent areas of exploration for the Committee is the question about capacity assessments and also identifying risk factors for coercion or duress being present where there is an applicant for voluntary assisted dying [VAD]. The proposed clause 180 of the bill sets out what should be included in the approved training and other resources and subclause (b) suggests that there will be training and resources about assessing whether or not a patient meets the eligibility criteria. Has Health done any preliminary work in terms of identifying what that training might look like, what the resources might be, that assist in that task of assessing patients in terms of the eligibility criteria?

Ms O'SHANNESSY: Just on the legal side of things, I do not believe we have done any work to date on the matter. It is ultimately a matter of if the bill passes, then we would need to look at it. There are already a range of policy directives and guidelines in relation broadly to consent which would form the basis for any work that would need to be adapted in order to deal with that. And there are also extensive policies on end of life, about identifying in relation to end-of-life management, in relation to identifying people's wishes and beliefs and engaging with people on their decision-making.

Dr LYONS: I will just add that there is extensive policy guidance already which at the moment, given this legislation before the Parliament, we are looking at that policy guidance and what we need to strengthen, subject to it passing. We are also thinking about what will be required in terms of ongoing education for all health professionals. We are very conscious that there is extensive work already. We have got examples such as our policy around recognising elder abuse and some of the factors that healthcare professionals might want to consider when they are providing care to elderly people and what action should be taken if they have got concerns. We have also established a module with our Health Education and Training Institute that provides a module of education that our healthcare professionals have access to which can give them some further education guidance and support in how to recognise and act on.

We will need to look at not just the policies that exist, the guidance that supports those, but also the education and training that is available. We are very conscious that should this legislation pass, we will need to ensure that that is available not just to people who work in NSW Health but to all healthcare practitioners, whether they are in general practice, whether they are working as a specialist in private practice, whether they are working in private hospitals. So it is going to be a very important aspect of our implementation process to go through that and ensure that we have got the right resources in place and that we can ensure that people have access to that education and training to ensure that they are appropriately skilled and have knowledge to support this legislation. So it is going to be really important work, which is why the 18 months, we see, is really critical.

It seems like a long time, but there will be a lot of work required from us to develop all of those resources and to do that in consultation with appropriate colleges of specialists and also with consideration to the legal and ethical aspects as well. I think the benefit for us will be that, given that there are a number of other States that have already gone down this path, we are already in contact with them to understand what they have put in place and to ensure that we can build on their learnings and ensure that we have the optimal arrangements in place to support our healthcare professionals if this legislation passes.

The Hon. TREVOR KHAN: Can I ask a follow-up question to that?

The CHAIR: Yes, sure.

The Hon. TREVOR KHAN: I say this in the context that my father was a general practitioner. What interests me is we hear from a lot of doctors about their interactions with their patients but, particularly in the hospital setting and also in the home-care setting, the health practitioner, if that be the right term, who has the most—and regular and indeed more informal—contact with a patient, is actually the nursing profession. They are more likely to see a patient interacting with relatives, both in the hospital setting and in the home setting, as opposed to the doctor, who is likely to see the patient with everyone else pushed out of the room, for instance. It is a more informal and interactive experience, in my perception. So if you are providing training, is it anticipated that you would provide training on coercion and the like also to the nursing profession?

Dr LYONS: Absolutely. All of our training is for healthcare professionals of any type, so it is not whether you are a doctor or a nurse or allied health. It is available to everybody. Our expectation would be that people who are involved in providing end-of-life care should absolutely be the target for this education and training and material, and that it would be applied to all of the healthcare professionals. The other thing is in our context we work in multidisciplinary teams so that everyone in the team is an important part of that team and has a part to play in ensuring that the wishes of the patient, the carers, families are actually met. So if there is an interaction where somebody learns that somebody has a desire or a wish or wants to make a choice, that person should be communicating with the rest of the team around them.

The Hon. TREVOR KHAN: If we go to clause 10 of the bill—I hope I am right in saying it is clause 10—yes. I will deal with clause 10 (2), as opposed to clause 10 (3), where we are talking about a medical practitioner initiating a discussion with a patient. That could be in the context, could it not, when we start talking about multidisciplinary teams, that the patient has already communicated a desire to look at the option with the nurses, say, on the ward or with a community health nurse? What clause 10 (2) really provides is that the doctor who has already been informed of the patient's wishes can essentially follow up and initiate the discussion. If you did not have that, a patient could be communicating with nursing staff and yet the doctor sort of has to sit there plaiting beads, without being actually able to have a discussion which he knows is actually already occurring with other health professionals. That is why that sort of clause is necessary, is it not?

Dr LYONS: I think from my reading of this clause, the critical issue is not just around the fact that the medical practitioner will become involved in having those discussions, but the importance about the holistic discussion, which is it is not just about one component. It is actually around a range of options that are available and the choices that should be available, and that those should be shared so there is complete sharing of all of the options and that then the option around the choice is made by the individual and their family.

The Hon. TREVOR KHAN: I have stolen Mr D'Adam's—

The Hon. ANTHONY D'ADAM: No, I am happy for you to.

The Hon. GREG DONNELLY: Doctor, did you say the individual and the family?

Dr LYONS: The individual will make the choice but, of course, they usually—as with every situation, people always talk to their family about these particularly important decisions.

The Hon. GREG DONNELLY: I invite you to have a look at the questioning from the Hon. Trevor Khan in regard to the early part of the evidence today, where he specifically dealt with a line of questioning where there is a rift in family member relationships and the fact that—

The Hon. TREVOR KHAN: Not an uncommon thing, Greg.

The Hon. GREG DONNELLY: No, but I invite you to have a look at that because he is talking about the circumstances where there is absolutely, under the legislation, no necessary obligation of any discussion whatsoever between the patient ending their life under VAD and family members.

Dr LYONS: All I was talking about is the usual circumstances in clinical care, Deputy Chair.

The Hon. GREG DONNELLY: Okay.

Dr LYONS: It was not a reflection of the particular reference to this bill.

The CHAIR: I will allow Mr D'Adam to continue his line of questioning.

The Hon. ANTHONY D'ADAM: You have indicated that you have been in discussions with other jurisdictions to try to glean the lessons of their experience. Are you able to elaborate on some of the feedback that has been provided by the other jurisdictions about the role that is played by the health administrative system in the implementation of VAD?

Dr LYONS: Yes, it is early days. There is an established process for the States that have this legislation to continue to meet and to work through. As you are aware, various States are at different time frames, depending on when their legislation was passed, and some of them are still working through implementation processes, as we will be. But there is another meeting of that group scheduled for 21 December and they will be ongoing, and it is our intention to continue to work with them. Subject to this legislation passing, what we would probably do is formalise that through our secretary writing to the secretaries or directors-general of the other health departments to ensure that we have got a formal process established to ensure we can share openly what has been done in those other States and what we can learn from.

The Hon. GREG DONNELLY: Thank you both for coming along this morning. The Chair clarified this in his opening statement, but can I make it very clear that you are not here today representing the Government. You are here as representatives from NSW Health. That is my understanding. I presume, though, that you are both here on the request or the direction of the secretary, Ms Elizabeth Koff. She has asked you both to attend today?

Dr LYONS: That is correct.

The Hon. GREG DONNELLY: With respect to the bill itself and the provisions of the bill, which is the substance of this inquiry, can I ask what legal analysis has NSW Health done into the bill, as a black-letter law analysis of a proposed piece of legislation that is going to provide for VAD?

Ms O'SHANNESSY: We have looked at the legislation in other States and Territories and identified that there is a degree of similarity with those laws, but not to any great degree because this is a matter primarily for Parliament and the judgement of Parliament. It is a private member's bill so we would not usually go into in-depth analysis of matters that are not government legislation and generally proposed through the Health portfolio.

The Hon. GREG DONNELLY: So, just to be clear, at this present point in time—it is 13 December 2021—NSW Health has not undertaken a detailed analysis of the second print of the bill, namely the bill that is currently before the Legislative Council. Is that your answer?

Ms O'SHANNESSY: It has been reviewed, yes, but not in detail.

The Hon. GREG DONNELLY: With respect to the review, can you outline what that has entailed?

Ms O'SHANNESSY: It has primarily entailed reviewing the bill and looking at its consistency with other States and Territories because, as Dr Lyons has indicated, if the bill passes and if Parliament determines to pass the bill, it will be a matter for us to implement it. One of the main issues from my perspective is the time frame available from an operational perspective for the system to implement the bill. I must say I am very pleased it is 18 months because, as Dr Lyons has said, it is an enormous task. Most of our implementation of legislation largely relates to the operations of the public health system. This is a statewide remit. This means we need to engage very closely with representatives of all the medical groups involved and the community. So it is ensuring we have a process in place for implementation, I think is the key issue.

The Hon. GREG DONNELLY: So with respect to the review that has taken place—that is the language you used—

Ms O'SHANNESSY: When I say a review, it is a review with a small "r".

The Hon. GREG DONNELLY: Okay, a review with a small "r". If I understand your evidence correctly, that review has involved some or complete comparative analysis with the other jurisdictions in Australia that currently have legislation in place, excepting that only two are operational, namely Victoria and Western Australia. Have documents been produced in regards to that analysis?

Ms O'SHANNESSY: No, there is just a table we have when we are comparing them. The other thing I think it is important to note—

The Hon. GREG DONNELLY: Sorry, without cutting you off, on notice could you provide a copy of that table to the Committee?

Ms O'SHANNESSY: Yes.

The Hon. GREG DONNELLY: So—

The CHAIR: The witness was continuing to answer when you asked for clarification. I will provide the witness the opportunity to complete her answer.

Ms O'SHANNESSY: Thank you. I was going to say that the bill is still in the House; it has not been settled and I am not aware if there may be further amendments in the Legislative Council. So, really, a prudent lawyer or administrator would be waiting for Parliament to make its call before we went into the detail of the analysis. That analysis will also help us decide how much we can engage with our colleagues in relation to the provisions they have.

The Hon. GREG DONNELLY: Yes, but can I put this to you? I am sure you are both aware of this, but NSW Health has a body called the Health Ethics Advisory Panel. Is that correct?

Ms O'SHANNESSY: Yes.

The Hon. GREG DONNELLY: At its last meeting, the members of that committee were provided with a briefing with respect to VAD. Is that correct?

Ms O'SHANNESSY: I am not aware of that; I do not attend the meeting.

The Hon. GREG DONNELLY: Dr Lyons, are you aware of that?

Dr LYONS: I am not aware, Deputy Chair. I do not attend the meeting either, so I was not aware that that occurred.

The Hon. GREG DONNELLY: Right. On notice, can you please provide to the Committee the details and copies—if there were—of presentations, power points, notes or whatever that were utilised by NSW Health officials at the briefing of the members of the Health Ethics Advisory Panel?

The Hon. TREVOR KHAN: Point of order: These witnesses are not here on behalf of the Government. They are here giving evidence with regards to their knowledge of matters. What is being asked are not questions going to their knowledge of matters but for them to embark on an exercise, on behalf of this Committee, of squirrelling through government to obtain documents. I suggest that in the context of a private member's bill and the context in which these witnesses are attending, that is not an appropriate course of action.

The Hon. GREG DONNELLY: To the point of order: We are looking at an inquiry into the provisions of the bill. There is no contest about that. We have established the basis upon which the witnesses are here today: They are representing NSW Health. In fact, they have been directed to attend by the secretary—or by us to attend on behalf of the secretary—of Health in New South Wales, Ms Elizabeth Koff. There was a briefing that took place very recently—

The Hon. TREVOR KHAN: Which did not involve them.

The Hon. GREG DONNELLY: No, but they are the representatives—

The CHAIR: Order! I will hear Mr Donnelly on the point of order. If you can, please be succinct on the point of order, Mr Donnelly.

The Hon. GREG DONNELLY: Listen, please. They are here representing NSW Health. There is a body called the Health Ethics Advisory Panel that is under the direct remit of NSW Health; it operates that entity. I accept that the two witnesses were not present at that meeting; I accept their evidence in that respect. But the matter of the bill was discussed at the meeting, so it is perfectly reasonable for the witnesses, if they were not present, to be invited on notice to establish what was covered by NSW Health at that meeting, which discussed the provisions of the bill.

The Hon. TREVOR KHAN: To the point of order: It is not just simply a question of them not having been there; it seems from the evidence that they are not members of that committee and, indeed, we do not know who prepared this presentation—

The CHAIR: I am prepared to rule on the point of order. This is an inquiry into the bill and the provisions within the bill. While the witnesses are representing NSW Health, I do not believe it is in their remit to provide these documents. Mr Donnelly, there is probably some other way in which this matter could be addressed, but I do not believe it is the requirement of these witnesses to provide those documents in these circumstances. I invite you to perhaps look at some other methods, and I ask you to move onto the next set of questions.

The Hon. GREG DONNELLY: Okay. With respect to the review—with a small "r"—work that has been undertaken, are you able to provide a copy of the schedule?

Ms O'SHANNESSY: It is a table comparing the different jurisdictions.

The Hon. GREG DONNELLY: Thank you very much. Are there any other documents that you have prepared or are aware of that deal with, look at or comment on the provisions of the bill by NSW Health?

Ms O'SHANNESSY: No.

The Hon. GREG DONNELLY: There is not?

Ms O'SHANNESSY: Not that I am aware of.

The Hon. GREG DONNELLY: Dr Lyons?

Dr LYONS: We have had very preliminary discussions, Deputy Chair, around the implementation requirements. We are turning our mind to what will be required of us if the legislation is passed and what things we will need to put in place, because we are very conscious that there is an extensive amount of work to support the effective implementation of the bill. We have had a couple of meetings now and we have started to have conversations with our clinical teams about the sorts of things that we will need to put in place to ensure that we do this effectively.

The Hon. GREG DONNELLY: So there are no documents?

Dr LYONS: Not that I am aware of.

The Hon. GREG DONNELLY: May I ask this question? I want to be clear that I am not being clever about this, but the witnesses are here today representing NSW Health. The Government does not have a position on the bill. With respect to the bill and the provisions of the bill, which is what this inquiry is about, the only work that has been done, effectively, if I understand the legal representative of NSW Health, is a small "r" review of the provisions by creating a comparative analysis table. What are we able to ask you in terms of questions to do with the provisions of the bill? Are we able to ask you specific questions about what provisions of the bill mean and you take those questions on notice or, based on what you have just said, Dr Lyons, you are not able to answer specific questions we may direct to you about the provisions in the bill?

Dr LYONS: It is very early days in terms of our responsibilities because the bill has not yet passed. As my colleague indicated, we would usually wait until legislation has passed and then look at what the legislation entails and what our responsibilities will be for implementation. We have started to consider that, as we always do, because we are quite prudent and want to ensure we have implementation delivering effectively. But it is very early days. We can provide answers to the best of our knowledge on the basis of where things are at at the moment, but it is not an extensive implementation plan at this point in time. We have some concepts and ideas about the sort of work that will need to be done, the areas we will need to focus on and the relationships that we will need to establish to ensure we can deliver effectively, but it is very early.

The CHAIR: Deputy Chair, I am just going to raise procedural fairness. This Committee determined that the scope with which NSW Health would appear would be very limited. It is not that the witnesses are not prepared to answer; it is that this Committee has been succinct in its questioning because of the provisions we applied to ourselves in relation to the representatives from NSW Health, and also the scope with which we are looking at the provisions of the bill. I just want to make that clear for the procedural fairness issues, so that there is no suggestion that these witnesses are not providing full and frank answers to any questions.

The Hon. GREG DONNELLY: Thank you, Chair, and just to be absolutely clear, there was obviously no suggestion, implicit or explicit, about that. For the record, can it be shown that at the first deliberative meeting with respect to this inquiry, it was I who raised the issue about government representatives appearing before the inquiry and ventilated an argument or discussion around the table for about 20 to 25 minutes, if I recall.

The Hon. TREVOR KHAN: Very lengthy.

The Hon. GREG DONNELLY: No, this is a serious point.

The Hon. TREVOR KHAN: Yes.

The Hon. SCOTT FARLOW: It was, really.

The Hon. GREG DONNELLY: Government representatives would come to the inquiry knowing how this matter has been dealt with in other jurisdictions. My question was, that being so, what would we be able to canvass with them in terms of our discussion? What I guess I am a little bit confused about then is with respect to—which we will come to shortly because we have plenty of time—questions about the provisions of the bill, that is, the bill that has passed the Assembly and is now before the Council and obviously is not yet passed by the Parliament. What do you see as the questions I can ask? May I ask you questions and you take them on notice?

The Hon. TREVOR KHAN: Point of order: It is not for these witnesses in that sense to be cherrypicking. Apart from any resolution that this Committee has made, what we also have is the fact that there is a procedural fairness resolution which limits what you can ask public servants. I think the other problem in this is that these are members in a broader sense, these are public servants with a bill that is before the House.

The Hon. GREG DONNELLY: Right.

The Hon. TREVOR KHAN: If one is going to talk about, in a sense, the comity of proceedings, then inviting public servants to be embarking on essentially a discussion of a matter which is before Parliament and to have them opining on provisions of a bill, I think it is highly problematic indeed and unfair on these witnesses.

The Hon. GREG DONNELLY: That is a point of order, so I am entitled to respond to that.

The Hon. TREVOR KHAN: You are.

The CHAIR: I will listen to the response.

The Hon. GREG DONNELLY: To the point of order: What I put to the representatives here—and let us be clear that they are here under the direct instruction of the Secretary of Health of the State of New South Wales to represent NSW Health, so we are talking about, dare I say, people at the most elite level who are here at the table. I proposed the placing of questions on notice; in other words, I could raise a question with you with respect to the matter of a provision of the bill. Please, I think it is a bit unfair to cast my suggestion that there be questions and expecting you to opine on the run. That was never my intention.

The Hon. TREVOR KHAN: And that is not what I am putting.

The CHAIR: So I think I—

The Hon. GREG DONNELLY: I have not finished. With respect, I have not finished my contribution to the point of order.

The CHAIR: I would ask the member not to talk over me. I was going to bring you back to speaking to the Hon. Trevor Khan's point of order.

The Hon. GREG DONNELLY: With the greatest respect, that is exactly what I was doing.

The CHAIR: Thank you, Deputy Chair.

The Hon. GREG DONNELLY: Right. So my question is, am I able to—

The CHAIR: We are addressing the Hon. Trevor Khan's point of order.

The Hon. GREG DONNELLY: Yes, that is right. So the position is that Mr Khan is saying, if I understand him, properly understood, that I cannot actually pose questions either to provide here before us today or on notice questions about the provisions of the bill—that is if I understand what is being said. If that is the ruling, what can we ask questions about? This is an inquiry into the provisions of the bill, not the provisions of the Act but the provisions of the bill.

The CHAIR: I am prepared to rule on the point of order. I uphold the point of order taken by the Hon. Trevor Khan in that this Committee is responding to the procedural fairness resolution of the House and that does limit the questions that we are able to pose to public servants. I will also note that the Committee itself resolved to restrict the questioning to the terms of reference.

The Hon. SCOTT FARLOW: Correct.

The CHAIR: And also that the witnesses were to be informed that this is not a government bill and the Government does not have a position.

The Hon. SCOTT FARLOW: Correct.

The CHAIR: The witnesses are appearing on invitation by the Committee, through me.

The Hon. GREG DONNELLY: Not representing the Government.

The CHAIR: Correct, not representing the Government, representing NSW Health, and they are here to provide responses which may be along the lines of: If this provision in the bill is to be enacted, what are the mechanisms with which that may be brought through perhaps a process within NSW Health? But their opinions and their ability to answer questions on a bill that is before the House and is still yet to come out of the Legislative Council is, as the Hon. Trevor Khan says, limited. If we adopt those positions, then they are the parameters within which we can ask questions of the witnesses now. Does that help?

The Hon. GREG DONNELLY: If I understand you correctly, what you are essentially saying, Chair—and I am sorry if this is not the way to behave, having discussions in this way, sideways with the Chair—is that if Mr Khan's proposition stands, I am effectively extinguished in the main from being able to raise questions to be either answered or taken on notice from the most senior representatives from NSW Health who are here today on the instructions of the Secretary of NSW Health to deal with what are the terms of reference of this inquiry into the provisions of the bill. My ability to raise questions with regard to the provisions of the bill with these representatives is effectively extinguished.

The Hon. TREVOR KHAN: Can I just comment? One of the problems with a private member's bill and one of the problems, let's be frank about this, with abortion reform was that a large part of the criticism was that the Minister had jumped into the fray and was expressing a position with regards to various components. This bill is entirely different. This is a bill where there has been no expression by a Minister or the Government as to what is the position.

The CHAIR: I am going to—

The Hon. TREVOR KHAN: Just hold on. Individual Ministers have expressed views in debate in the House.

The CHAIR: Correct.

The Hon. TREVOR KHAN: But the Government, the Executive, has not adopted a position. What is therefore being sought, with regards to particular provisions of the bill, is for these witnesses or other lawyers somewhere in Health to jump into the fray and give expressions as to the interpretation of provisions of the bill. That is precisely contrary to the position of the Government not having a position. You cannot use the functionaries of government for the purposes of commenting on something that is before the House as a private member's bill. That is the real problem.

The CHAIR: This is the position that I am going to take.

The Hon. GREG DONNELLY: Sorry, can I say something?

The CHAIR: Can I address this?

The Hon. GREG DONNELLY: All I want to say is—

The CHAIR: I am actually making my—

The Hon. GREG DONNELLY: —he is extinguishing my position.

The Hon. TREVOR KHAN: You can ask him.

The CHAIR: No, he is not, and I am about to comment on that. If both members would allow me, please, I am very much trying to keep the temperature low in this room today. My position is that any member of this Committee can ask any question they like. It is then up to any other member of the Committee or me to raise a point of order or for me to rule the question out of order. The Hon. Greg Donnelly is entitled to ask any question that he sees fit. It is up to any other member to seek a point of order or for me to rule the question out of order. I invite the member to ask his questions but I am foreshadowing that if they are outside the parameters that this Committee has set, then that is potentially the outcome that will occur. I will give the Hon. Greg Donnelly the call to ask his further questions and then I will pass to the Hon. Anthony D'Adam, who has indicated that he has questions.

The Hon. GREG DONNELLY: Perhaps pass to Mr D'Adam and we can circle back.

The Hon. ANTHONY D'ADAM: I want to come back to the question around capacity assessments. Perhaps you might be able to advise the Committee: Are there other contexts, aside from voluntary assisted dying, where clinicians in the health system are likely to make capacity assessments?

Ms O'SHANNESSY: I will go with the legal issue first. Yes, across the board all the time in relation to—if you look at the NSW Health Consent Manual, which is a comprehensive document which deals with the taking of consent for medical treatment and medical care, a critical element of that is obtaining consent. And it can occur—the presumption, as I believe you heard from the Bar Association and others in earlier evidence, is that a person has capacity, but it is a matter for clinicians on a daily basis when they are dealing with patients to make those assessments. Obviously one of the issues with the test of capacity is that, the more complex and impactful the treatment is, the greater the assessment about the person's full understanding of all those issues. So it is a daily matter for clinicians, and Dr Lyons might be able to talk on the practical level.

Dr LYONS: On a practical level, this is what clinicians do all of the time because they are in constant dialogue with the patient about decision-making, decisions to undertake, diagnostic tests that might have potential adverse consequences, decisions around what the diagnosis is and what treatment options are available to the person and their choices around what treatment they would like to receive, details around decisions on medications and what medications might be offered—all of those things are done on a regular basis by clinicians all the time. It is part of regular clinical practice.

The Hon. ANTHONY D'ADAM: Is there specific guidance that Health provides in relation to making those kinds of capacity assessments?

Ms O'SHANNESSY: I would have to defer on if there are sort of clinical protocols but, as I said, the New South Wales Consent Manual, which I think was only published two years, or one year, ago—sorry, COVID time—is a detail of all aspects of consent and it looks at different situations with consent. The fact that simply because someone has a disability does not mean that they do not have capacity to consent.

The Hon. ANTHONY D'ADAM: I am happy for you to take it on notice and perhaps if relevant extracts of the documents can be provided.

Ms O'SHANNESSY: The document in question is publicly available on our website too, so it would be useful. It is a very big document and there is quite a bit dealing with capacity.

The Hon. ANTHONY D'ADAM: Yes, that would be appreciated. Also earlier, Dr Lyons, you referred to the guidance that has been provided around elder abuse. Perhaps you could also provide that guidance to the Committee.

Dr LYONS: Certainly.

The Hon. TAYLOR MARTIN: Just following off that line of questioning from Mr D'Adam, particularly in regards to elder abuse—it was mentioned in the opening statement. Would there be guidelines established and provided for doctors to be able to use when assessing coercion? We heard from a doctor last week in regards to this that they had concerns in relation to assessing coercion.

Dr LYONS: There is not a detailed comment around coercion in the elder abuse guidelines, but one of the things that we are conscious of is, given the wording of this bill, our need to review current guidance to ensure that we are providing appropriate support, education, training and capability assessment for our clinicians around these very areas because this has been emphasised in this proposed bill that it is very important. It is not just the skill and capability, but my reading of the bill is that it is actually around process as well. There are processes that have been built into the bill to provide additional protections, but it is important that we give our individual practitioners as much guidance, support and direction around those areas and capability as we possibly can. So that will be one area of a review.

The Hon. TREVOR KHAN: Could I just ask a question that follows up on that. If you go to the manual on consent—I think that is what it is called, isn't it—at 4.3, it is a very lengthy part, but four criteria must be met: the patient giving consent must have capacity, the consent must be freely given, the consent must be sufficiently specific to the procedure or treatment proposed, and the consent must be informed. That is the style of thing that is provided in the manual.

Dr LYONS: That is correct.

The Hon. TREVOR KHAN: And it is very lengthy manual, it seems.

Dr LYONS: Very comprehensive.

Ms O'SHANNESSY: But very easy to read, having used it myself recently. I think you will find too there is a detailed description of each of those core components of what consent means in the manual as well.

The Hon. TREVOR KHAN: Indeed, you talked about various medical procedures. The nature of consent for instance goes to issues for instance of pregnancy and the termination thereof. In a sense, some at this table would say matters of life and death are already dealt with in some detail in the manual.

Dr LYONS: Correct.

The Hon. GREG DONNELLY: Except the position is that in fact the document referred to is a document which is internal to NSW Health and applies to the organisation known as NSW Health, isn't it?

Ms O'SHANNESSY: Yes.

Dr LYONS: That is correct.

The Hon. GREG DONNELLY: So, with respect to those provisions that have been just referred to and, dare I say, elucidated on by referring to them, those provisions do not apply to, for example, GPs that may be working around the State. Is that correct?

Dr LYONS: Not directly. However, in my experience, what occurs—

The Hon. GREG DONNELLY: No. I asked a question—

The Hon. TREVOR KHAN: No, he is entitled to answer the question.

The CHAIR: Order! I will allow Dr Lyons to complete his answer.

Dr LYONS: Not directly. But the experience that I have had working in the system now for 35 years is that the guidance that NSW Health provides to clinicians working in the NSW Health system is actually very important in the context of the delivery of care in other settings. The reason for that is that we are seeing often—and this has applied very strongly during the last 18 months or two years with responding to the COVID pandemic—that the guidance, advice, direction that we provide to our clinicians is seen as a very important signal to other clinicians about the activities, the practices and the approach that they should take in delivering care in the settings that they are delivering care in as well, and in fact they look to us for that guidance and support. The other aspect, of course, is that in common law, in terms of decisions around if a clinician were subject to some concerns around the practice and their approach, the policies and guidance that apply to practitioners generally would be considered to be the sorts of things that would be taken into account. So there is no mandatory requirement, but it has a very strong influence over the practice of clinicians outside of the NSW Health system.

Ms O'SHANNESSY: I think that is the distinction. It is mandatory within NSW Health but a highly influential guide for the broader system.

The Hon. GREG DONNELLY: I did understand that. It is well known in, dare I say, the health ecology of New South Wales—what you have just said. Could I just go back to the point you made in your opening statement, Dr Lyons, about the strengthening of the guidelines. You will recall in your opening statement that in light of this legislation passing Parliament there would be a strengthening of the guidelines. That is what you said. Can you explain what that means?

Dr LYONS: What we would do is—

The Hon. GREG DONNELLY: Sorry, just explain which guidelines we are talking about. If we are talking about the same ones or different ones, just be clear about that.

Dr LYONS: So the guidelines that exist and have been mentioned, I think I have made reference to the elder abuse, we have made mention to the consent to treatment, these guidance—

The Hon. GREG DONNELLY: Sorry, these are all the guidelines—

The CHAIR: Order! The question has been asked. Can we allow Dr Lyons to complete his answer? If you need to then seek some further elucidation, then Dr Lyons can provide that, but in the first instance they need to be able to finish their answers first.

The Hon. GREG DONNELLY: Point of order: The language "guidelines" was used in the opening statement. All I am simply wanting to clarify, because I think it will just make the whole thing much more clearly understood, is whether there is a single set of guidelines that you are referring to—in other words, guidelines that we just mentioned one of in my previous line of questioning—or are there a set of guidelines? That is what I am trying to understand.

The CHAIR: The issue that I have got is that Dr Lyons was no more than about 10 words into his answer before he was interrupted. He may have been coming to that. The way that we treat witnesses when they are here is that we ask a question, they provide a response. If you then seek further information you are allowed to seek an elucidation. Dr Lyons, if you could provide a response, I would appreciate that.

Dr LYONS: I might ask my colleague to respond to the guidance and the sets of guidance.

Ms O'SHANNESSY: It might be very helpful to give you some context. Across NSW Health there is a comprehensive set of what we would call policy directives, which are mandatory, and guidelines, which are supportive of those. What I would suggest we would be doing would be—and I think Dr Lyons was speaking generally in relation to our guidelines on various issues with the two examples of the elder abuse policy and consent manual—looking at all our current policy directives and guidelines to identify whether they overlap with matters dealt with by the bill to make an assessment of them and see if they need to be revised. In addition, there are a series of matters that the bill requires the Health Secretary to produce guidelines about. For example, the consent manual may well have a new part on all the requirements of consent required by the bill, or we may decide to do something separate for that given the specialist nature, and then there needs to be consideration of how then it applies broadly beyond NSW Health. That would be the kind of process. That is more of a context that hopefully is helpful.

The Hon. GREG DONNELLY: That was the next part. Thank you for that. That has been very helpful. Forgive me, we all understand this but I just want to be very clear, you are representing NSW Health here. I just want the record to be very unambiguous about this. There are the policy directives, which sit at this particular level. I presume above that is the statute law and common law of New South Wales. Is that how you would place this in a hierarchy?

Ms O'SHANNESSY: Yes.

The Hon. GREG DONNELLY: You have got the policy directives. What is the actual legal standing, may I ask, of policy directives?

Ms O'SHANNESSY: Policy directives are mandatory within the public health system. The legal source is that all entities in the public health system are subject to a subsidy from the Minister for Health under the Health Services Act. That subsidy can impose conditions on the subsidy. It is a condition of subsidy that all entities in NSW Health comply with those policy directives and the policy guidance system. We have a number of other entities that are entities of the Health Secretary, and there is also a directive from the Health Secretary that those entities comply with the policy directives.

The Hon. GREG DONNELLY: Thank you very much. That is very helpful. Then beneath them, as described by Dr Lyons, are guidelines broadly understood as various guidelines covering different domains that are believed to need guidelines. I presume that is why they are created in the first instance. What is the legal standing of guidelines?

Ms O'SHANNESSY: The guidelines form part of the policy directive system as well, but I think it is important to say there are actual formal guidelines. If you look on our website, all of those policy directives and guidelines are freely available, and you will see some of them are called "PD"—policy directive—"2011_004" and some of them are formal guidelines, "GL" with the year and the number. They are all applicable across the NSW Health system and each of them will tell you on the front exactly the range and extent of coverage, but then there are other clinical protocols which may be internal or guidance documents or developed by statewide clinical groups, which perhaps Dr Lyons may be able to talk to in more detail.

Dr LYONS: Supporting those guidances there will be clinical pathways and models of care. This is guidance that is developed by clinicians and clinical teams to support the delivery of care in a consistent and evidence-based manner. They are usually developed as a result of the policy directive and the guidance that exists and that flows down into what that means for this group of patients. How we provide care is directed by those things and then there is a development of a more explicit clinical guidance around that particular patient or patient group, and that is done by the clinicians and clinical teams.

The Hon. SCOTT FARLOW: I have a bit of a different line of questioning. Thank you very much for your attendance here today. I am just interested, in terms of the voluntary assisted dying substances—and I do not know if you have any knowledge of these—how many different substances would there be that would fall under that category from your knowledge?

Dr LYONS: It is not something that I have direct knowledge of, and so I would have to take that on notice and provide the Committee with that advice.

The Hon. SCOTT FARLOW: There was also a suggestion the other day that an amendment to the bill could be that such a substance be approved by the TGA to provide an additional safeguard. Do you see any impediment with such an amendment or any impracticality there?

Dr LYONS: Let me take it on notice, but my general comments would be that it is almost invariable that medications that we deliver in the healthcare system have been through that process. The only situation where they have not been through a formal TGA process is where they are the subject of clinical trials and are currently under research arrangements, and there are heavy safeguards around their use in that context as well.

The Hon. SCOTT FARLOW: Just on that point as well, can you take on notice as well what voluntary assisted dying substances have been approved by the TGA?

Dr LYONS: Certainly.

The Hon. GREG DONNELLY: Returning to the line of questioning about the framework we were discussing before we had to move to other members to ask questions, we have the guidelines and I think they have been covered quite thoroughly. Thank you for that. I think the evidence from you, Dr Lyons, is that there is going to be work done. That is in the implementation I presume with the 18-month window. You mentioned that there will be work done to strengthen the guidelines. I think they were the words that you used. Is that to also be meant to understand to strengthen the policy as well, or, in other words, strengthen all of those matters that fall within that remit of what New South Wales actually basically prepares for itself and uses as its documents, be they called policies or guidelines?

Dr LYONS: I think once the legislation is passed it would then be that we would assess the application of that bill and what it means in the context of all of our policies, procedures, practices, education and training material, the systems that we need to set up to support its effective delivery, and we will make that assessment and we have started to already think about the sorts of things that we will need to do and what processes we will need to establish to ensure that we deliver on all those. We are already thinking about establishing a steering group for the implementation of the bill and its implications in New South Wales and then a subset of working groups that will need to be established. We are thinking about who needs to be on the overarching steering group, what their relationships need to be and the sorts of groups it will need to involve. We are also thinking about the work program that would fall underneath that to ensure we could effectively deliver. That preparation work is already being considered.

We have already had discussions with a number of our senior clinicians about the intersection with other clinical services and clinical care and the need to assess in those contexts what advice, guidance and support we might need to provide, and in particular at the intersection with palliative care. That is a discussion that we have already started to have and the criticality of our palliative care services being appropriately supported to enable this legislation to be applied in a way which is about promoting choice and not being an either/or and that our services are supported in assisting people to make appropriate decisions around those choices.

The Hon. GREG DONNELLY: Thank you for that, and it is a matter I will come to shortly. Before I do so, just to be clear, this was touched on in answer to my question, and I am not cavilling with your answer at all, about the persuasive nature—I will use that phrase and they are not your words—or the persuasive value of policies, guidelines and protocols of NSW Health to the health ecology of the whole of New South Wales. That is true. I think there is not anyone who contests that; certainly, I do not.

My question is once one has gone through this process of doing all of this work with respect to all that you have described with respect to these matters of the policies, guidelines and protocols and they are all put into place, they are there, the scheme is operational—we are looking down the track—with respect though to being legally bound by the policy, guidelines and clinical protocols, it is the fact though that it is only employees of NSW Health who are strictly bound by those. Is that not the case? Setting aside what you have said about the persuasive influence, as a matter of law you cannot bind a general practitioner who might be operating out at, dare I say, Timbuktu in regional New South Wales and argue—and if you are arguing this, please say this before us—that your policy directives, guidelines and clinical protocols apply to that general practitioner.

Dr LYONS: Do want to make a comment first and I will add?

Ms O'SHANNESSY: I think you have got to look at it in the context that the bill itself identifies a large range of matters that the secretary has to produce guidelines under to enforce the legislation that will be applicable and enforceable across the public and private sector.

The Hon. ANTHONY D'ADAM: So those guidelines will be enforceable, will they?

Ms O'SHANNESSY: That is a matter for the terms of the bill. These are requirements. That is how the bill would work. You are saying they are required—I would have to double-check. You would know the bill better than I would, what it says about breaching any guidelines. I am not sure what it says. But beside that you have a piece of legislation that—we have other pieces of legislation. For example, the Poisons and Therapeutic Goods Act regulates the use of medicines in New South Wales. There is lots of guidance provided by Pharmaceutical Services as to "this is what you need to do to comply". So to that extent it is directing people. Again, part of that review would be to assess outside the specific guidelines required in the bill: Is there other information which is both educative, communicative and advisory about what people need to consider if they are going to be in compliance with the bill, or the Act if it is made?

The CHAIR: To seek some clarity, should the bill pass this Parliament, the requirement on a doctor—whether they be part of the New South Wales health system or in private practice within New South Wales—the provisions of the legislation by that stage would cover both of them. The guidelines and policies that are produced would apply to NSW Health doctors. However, the guidelines and policies are based off the legislation and the legislation covers both sets of doctors. Is that correct? That is effectively my read on it.

Ms O'SHANNESSY: There are provisions, from my recollection, in the bill that require the Health Secretary to issue guidelines on particular things. The source of power—

The Hon. TREVOR KHAN: Clause 182.

The Hon. ANTHONY D'ADAM: Clause 181.

The Hon. TREVOR KHAN: There we go, I was close.

Ms O'SHANNESSY: The source of power is the legislation, so that will apply across the board.

The CHAIR: So regardless of whether the guideline or policy is enforced by NSW Health—which is going to the question the Deputy Chair was asking previously—the legislation, which is where the genesis of those guidelines and policies was from, would still be the overarching factor for both sets of private and NSW Health doctors. Is that correct?

Ms O'SHANNESSY: Where those guidelines are required under the Act. In relation to enforcement, my recollection as well is that there are references that interact the voluntary assisted dying legislation with the existing national registration and accreditation system, and delineating certain things to be matters capable of being dealt with as professional misconduct, unsatisfactory professional conduct and other things. There is a whole regime around that with a range of protections, penalties and activities if there are breaches of what is considered unsatisfactory professional conduct or professional misconduct.

Dr LYONS: I was going to add to that. That interpretation is my interpretation as well. What then flows in practice usually is that the groups that support those doctors who are working in New South Wales in different ways will often come to us to seek the guidance and support that they will then adopt from either their colleges or their organisations to ensure that they are providing the appropriate support for their clinicians as well to ensure they are operating consistently with what the legislation requires. We are anticipating that that is going to be the case and we are starting to think about in the implementation approach which are the groups that we need to start to work with to ensure that happens almost seamlessly from the outset—that those things are being supported, that people are provided the appropriate guidance and advice and that it is flowing right through to the practitioners who work inside NSW Health but also in other settings outside Health.

Ms O'SHANNESSY: Can I also add that part of that process would also engage the current health regulators in New South Wales, which would be the Health Care Complaints Commission and the various health professional councils, which would be looking at the conduct of the clinicians.

The CHAIR: So it is effectively easier to plagiarise NSW Health's guidelines and policies.

Dr LYONS: We are very influential in that regard. I think people look to what we are doing in the New South Wales health system because it covers so many health practitioners in so many different settings. What you can see from what we have conveyed so far is the extent of work that is going to be involved, the consultation required. And from our point of view the 18 months is absolutely—we are probably going to use every day of it because there is going to be a lot of work involved in ensuring we have got all this in place.

The CHAIR: On that point, is the provision of 18 months suitable in your opinion for what you would envisage the amount of work to be?

Dr LYONS: I believe so, especially given that there are other States that are already well advanced. Some have already commenced their own legislation, others are well advanced in the preparation. We are very much of a view that we should be looking to what they have done and learning from it. The other thing we are very conscious of is that, as a nation, our clinicians work across the country. We want to try and ensure that there is as much consistency in the way we are applying the legislation—that is New South Wales legislation, notwithstanding—but thinking about the context of the fact that we want to get as much consistency around how that is undertaken as we possibly can.

The CHAIR: I am cognisant that the Deputy Chair had the call previously. I know the Hon. Anthony D'Adam wants to ask a question. The member can ask a question and then I will come back to the Deputy Chair.

The Hon. ANTHONY D'ADAM: I have a very quick question, which is, in spite of that exchange, I am still unclear about the status of the guidelines. Subject to this question being in order, I would ask on notice that you provide to the Committee your understanding, based on the second print of the bill, of the mechanism for enforcing guidelines under this bill. What would be the mechanism for enforcing, based on the second print? If that is in order, then I am happy for that question to stand, but otherwise—

The CHAIR: I am looking to see if anybody is going to take a point of order.

The Hon. GREG DONNELLY: No objection.

The CHAIR: I think it is appropriate, given that we are discussing the bill, and we have sent the second print to everybody so that we can ask questions on that.

The Hon. TREVOR KHAN: I do not think that is the basis. But clearly because NSW Health is developing the guidelines, I think we need to know how those guidelines play in this space—

The Hon. SCOTT FARLOW: Yes.

The Hon. TREVOR KHAN: —otherwise I would take the objection that I took before. But it does seem to me quite pointed in the scheme of things.

The Hon. ANTHONY D'ADAM: It seems essential. If we are going to understand the implications of the bill, we need to know.

The Hon. TREVOR KHAN: I think everyone at the table wants to know that.

The Hon. ANTHONY D'ADAM: If we are making guidelines, creating a guideline power, how is that going to operate?

The CHAIR: The question is in order. I will confirm: Are the witnesses happy to take the question on notice?

Dr LYONS: Yes.

The CHAIR: Thank you.

The Hon. GREG DONNELLY: It might sound trite to say but that is exactly where I was getting to before I was interrupted. With respect to the guidelines, we were talking about the development of guidelines that was going to be done in the context of the 18 months. I was talking about it at the very start of my back and forth with you. I am well aware of the provisions within the bill that deal with guidelines; thank you very much. But we are dealing with, as I understand it, potentially two sets of guidelines here—if I am not misunderstanding—and that is that we have these, dare I say, existing NSW Health guidelines that deal with matters like consent and elder abuse. There could be a number of others as well, at least some others, which are directly relevant to this legislation that is before us if it becomes an Act. I am sure you are thinking about these matters.

In the context of thinking about these matters is why you have turned your mind already to how they, that is, the guidelines that deal with elder abuse, may need to be—my words, not yours—toughened up or made more clear. Matters of consent may need to be refined somewhat—my words, not yours. So that process is being done, and they are guidelines, if I understand it, that will become NSW Health guidelines that, in your evidence, if I understand you correctly, would flow out beyond NSW Health to the medical health community in New South Wales to be persuasive, influential, in the thinking of medical practitioners in the State. Is that correct?

Dr LYONS: That is correct.

The Hon. GREG DONNELLY: So they are those guidelines. That is effectively the annunciation of the requirement of existing guidelines, but you have seen that they are apposite and irrelevant to the legislation and therefore there is work to be done to spread them out in a refined fashion. There are also the provisions in the Act with respect to the creation of guidelines and the relevant guidelines that are issued by the Secretary. Those guidelines could be on other issues, could they not, other than these ones? Is that correct?

Ms O'SHANNESSY: They could.

The Hon. GREG DONNELLY: So what we are talking about here—I am just trying to make this clear. This is not some ambushing exercise; I am just trying to understand this clearly. The proposition, as put, is that existing guidelines will be deemed to probably have some relevancy with respect to the operationalising of this legislation and therefore, in advance of that, you are thinking about how they—and not just "they", but how we can get them out there, so to speak, beyond NSW Health, beyond what is currently the position at the moment.

Dr LYONS: Yes.

The Hon. GREG DONNELLY: So that is what you are proposing. Then there is the second issue of guidelines that may be issued by the secretary. With respect to those guidelines that may be different from these particular ones that are already existing in a form within NSW Health, do you have an opinion or have you turned your mind to what those guidelines may look like?

Dr LYONS: Not at this point in time, I have not.

Ms O'SHANNESSY: I think there needs to be an assessment. The bill is very detailed and very clear on a large number of issues—very similar, as I said, to some of our other legislation. So the bill will largely, in many ways—or the Act, if it is passed—speak for itself. Part of our assessment process and engagement with the clinicians both in the public and private sector needs to be where there should be some clarity or additional guidance, consistent with the intent of Parliament. But until we look at that it is quite difficult, but—

The Hon. GREG DONNELLY: No, no, I understand that, but—

The CHAIR: Can we just allow the witness to complete her answer?

Ms O'SHANNESSY: Until we have done that process and there is a final bill, it is really quite difficult to say how far they will go.

The Hon. GREG DONNELLY: Just to be clear, though, just so I understand your evidence, with respect to the development of these guidelines prospectively, it is not the case that NSW Health, as the primary, principal health body in New South Wales, would itself, for example, take legal advice and make a determination about whether or not its own policies or guidelines perhaps need refinement, but that it is with consultation with the sector at large—that is how you create these policies or guidelines. Is that what you are saying?

Ms O'SHANNESSY: Yes.

The Hon. GREG DONNELLY: May I ask you, then, where does legal advice come into whether or not the guidelines, the policies, the working procedures meet the requirements of the law?

Ms O'SHANNESSY: I am not quite sure—we have gone from talking about whether we need guidelines to whether the guidelines are consistent with the law. Most of the critical policies, including the consent policy and other policies that are developed by NSW Health, are reviewed by my team in the legal unit.

The Hon. GREG DONNELLY: Okay. So that is, in effect—in my words, not yours—a serious check on the validity of—

Ms O'SHANNESSY: Exactly.

The Hon. GREG DONNELLY: No, no, no, I was not—

Ms O'SHANNESSY: No, sorry—

The Hon. TREVOR KHAN: We are talking over each other again.

The Hon. GREG DONNELLY: I am just trying to clarify this because clearly the law operates as what is binding, whether people like it or not, and it is very important, presumably, and without question that anything that operates under that domain of a policy or a guideline or a working procedure is in complete sync with the law as it is.

Ms O'SHANNESSY: And the legal advice would also say you do not need guidelines because the law is clear.

The Hon. GREG DONNELLY: Sorry, could you repeat that again?

Ms O'SHANNESSY: The legal advice would also look on the fact if there is even any need for guidelines, because the law is quite clear in the area.

The Hon. GREG DONNELLY: Right. Can you explain why New South Wales has policies, guidelines and procedures?

Ms O'SHANNESSY: Because there are many areas where there is no legal—I think this is a bit of a circular question. What I am saying is—

The Hon. GREG DONNELLY: No, it is not, actually.

The CHAIR: Order!

Ms O'SHANNESSY: —we have been talking about assessing a new piece of legislation, which is very detailed and very clear on many aspects, so there is no need for guidance. If we are talking, for example, about many aspects of our policies, the concepts of consent are very high level—we have already discussed them—and the policies and guidance provide detail about how to operationalise them.

The Hon. GREG DONNELLY: Can I just change my line of questioning to something slightly different, but directly relevant because it has been raised already by yourselves: the matter of palliative care and its importance and significance, and specifically in the bill? Can I ask a question of the witnesses about two provisions in the bill and just draw it to their attention?

The CHAIR: Absolutely.

The Hon. GREG DONNELLY: You would be aware that in the principles clause of the bill, in clause 4 (1) (d), there is reference to palliative care. May I just draw clause 4 (1) (d)to your attention? If you do not mind, I will read the lead-in sentence:

> A person exercising a power or performing a function under this Act must have regard to the following principles—

It then lists them down. Then we get to (d), which states:

> a person approaching the end of life should be provided with high quality care and treatment, including palliative care and treatment, to minimise the person's suffering and maximise the person's quality of life …

That is a clear principle enunciated in the bill. Can I just take you to page 4 and clause 10, headed "Health care worker not to initiate discussion about voluntary assisted dying"? I would like to take you to clause 10 (2) (c). In clause 10 (2), the lead-in paragraph states, "Subsection (1) does not apply" blah, blah, blah, but then it leads down to "also informs the person about the following—" and (c) states:

> The palliative care and treatment options available to the person …

If I could just go back to clause 4 and the question of the principles, can you explain to me, if you are able to do so, as a legal representative here, what is the importance or significance or value of principles in an Act of Parliament?

Ms O'SHANNESSY: Generally you have principles more broadly about the purpose of the Act—for example, the Public Health Act, which has been something on everyone's minds for some time; it has a set of principles about what its overall purpose is, and that helps in interpretation. This principle is actually directed at the person performing a function under this Act and it says they must have regard to those principles. So that is what it is telling the person performing a function under that Act that they have to do.

The Hon. GREG DONNELLY: Will there be employees of NSW Health—I am not being clever here but I am asking you just for the purposes of clarity. If this is passed and becomes operationalised, there will be employees of NSW Health, i.e. medical doctors, who will be operating under the provisions of this legislation, will there not?

Dr LYONS: Yes.

The Hon. GREG DONNELLY: And those individuals would be exercising power, performing functions under the legislation. Would that be correct?

Ms O'SHANNESSY: If it is a power or a function, yes.

The Hon. GREG DONNELLY: No, that is fine. With respect to those doctors—and let us just take a doctor anywhere in NSW Health who is working as an employee of New South Wales anywhere around the State—they will need to have regard for the principle specifically at 4 (1) (d); is that correct?

Dr LYONS: That is what the legislation, as drafted, says.

The Hon. GREG DONNELLY: Yes. So can you explain then the issue of the real situation of unavailability of palliative care to certain citizens of this State and what that means with respect to a doctor being able to fulfil obligations pursuant to that provision?

Dr LYONS: I make a couple of comments. The commitment to end-of-life care in New South Wales is strong. The New South Wales *End of Life and Palliative Care Framework 2019-2024* emphasises:

> All individuals should have access to the best possible end of life and palliative care – no matter where they live, their condition, age or who they are.

That is a current framework that is in place. In addition to that, NSW Health has the Clinical Principles for End of Life and Palliative Care guideline—one of the guidelines that was mentioned in previous evidence this morning, GL2021_016—which sets expectations for clinical services from the screening and identification right through to grief and bereavement, and has a whole series of priorities. We accept that there is a growing need for palliative care as we have an ageing population. As a result of that, there has been significant investments in palliative care over the last few years.

I think back in 2017-18 we had around $200 million per annum spent on NSW Health on palliative care, and the Government has invested significantly more over a number of the last budget cycles. In the 2017-18 budget, it announced an additional $100 million over four years. The 2019-20 budget allocated another $45 million over four years on top of that. The 2020-21 budget allocated an additional $56 million over four years on top of those further investments. Again in the 2021-22 budget, there was a further $82.8 million over four years announced. So there has been, over that period of time, probably another $100 million per annum. So it has been a 50 per cent increase in the budget and the funding that has been provided for palliative care services. Those investments are flowing out into the system now. We are very conscious of the fact that there are major challenges in delivering those services, particularly as you move further away from metropolitan centres, and the issues around workforce availability.

You and I have been listening to the testimony in the rural and regional health inquiry—some of the challenges of how we ensure that people have access to the best possible care in those communities. We have invested in additional palliative care specialists, additional community services, palliative care services, but the challenge remains in ensuring that everybody everywhere gets access to that care when they need it. So we are continuing to think about what further investments we need to make but, not only that, skilling up staff to ensure that we have got people with the capability available in those sites, so scholarships for education and training for nurses, allied health, GPs who are actually working on those centres already, and we are assessing the benefits of linking our specialist palliative care services with the services that are on the ground in those rural and regional communities.

You heard, I am sure, about virtual care and some of the opportunities that that creates. I was very fortunate to actually hear first-hand a great story from a person who gave evidence to us—it was not evidence but it was a story—at one of our bilateral rural and regional committee meetings in Dubbo about their experience with their wife, who died of a terminal illness in a rural centre and was provided the backup of telehealth through that terminal phase, and how much benefit it was to actually have access to that specialist advice over telehealth to enable care to be provided with support in situ. So they are the sorts of things that we need to continue to build on and ensure that we are providing optimal care to our patients and communities, no matter where they are in the State, and that we use the technology and the linkages that we have to support that care being provided optimally. We recognise that challenges still exist, but we are committed, through the guidance and the directions that I have outlined there and also the investments that are being made, to further improve those services.

The Hon. GREG DONNELLY: I will not read it to you again, but clause 4 (1) (d) of the bill states:

> … should be provided with high quality care and treatment, including palliative care and treatment, to minimise the person's suffering and maximise the person's quality of life,

The truth of the matter is that there are people today, tomorrow, next week, next month, probably even next year potentially, dying in circumstances where they do not have access to even—not the question of high-quality care—the most basic of palliative care because there are just not GPs in their local town. That was evidence we found all around the State. You would tell us that, would you not, Dr Lyons?

Dr LYONS: I have heard the evidence of the inquiry, yes.

The Hon. GREG DONNELLY: Yes, so there are not doctors in the town to be able to even prescribe for the basic provision of a syringe driver and pump associated with pain relief. That has been evidence, has it not?

Dr LYONS: Yes. So just on that evidence, yes, that evidence has been given, but there are mechanisms too for people to be able to access some of those treatments in those facilities through the arrangements that the districts have made. We have got Health nurse practitioners who are given prescribing rights. We are looking at expanding the range of those positions in rural settings to enable people to be able to prescribe if there is no doctor available, and we are also providing linkages through virtual care for provision of medications through an assessment that is being done virtually and appropriate supports available for the health practitioners on the ground to administer medications in certain situations. So the evidence has been given, yes, but we are acting very strongly and actively to address the issues around access and ensure we can provide the best possible care wherever people are being provided that care.

The Hon. GREG DONNELLY: I guess we will agree to disagree on that because, as far as I was concerned, the evidence was manifest around the State that the care was just not provided. Anyway, moving on, can I just ask you this question: In terms of the cost to NSW Health to implement the VAD scheme in the State, what work is being done in terms of doing some basic calculations in regard to the implementation of the scheme?

Dr LYONS: We have not done detailed analysis of the cost of doing that. Our core business is actually ensuring that we deliver on any legislation that is passed by government, any policy direction set by government. That is our task—to implement effectively and support that being provided. So we see those responsibilities as part of our core remit, and the resources we are provided to do so in the Ministry of Health will be applied to ensure that we are delivering on this effectively as well.

The Hon. GREG DONNELLY: Will it actually do work to establish the cost associated with the implementation of voluntary assisted dying?

Dr LYONS: We do not usually go through looking at costing exercises for every piece of legislation or policy that we are required to implement. If there are additional requirements in place—so one of the things that this bill requires is the establishment of the Voluntary Assisted Dying Board, and that will need to be provided some appropriate resourcing and support. We would, I suspect, cost that up to ensure that we provided in a budget ongoing support for that board. So those sorts of things will be costed up in due course, but we do not usually go through and calculate every component of implementation cost.

The CHAIR: Sorry, Deputy Chair. We only have a handful of minutes left. I want to go round the Committee and see if there are any other members who might have some questions before I pass to the Deputy Chair for a final set of questions.

The Hon. GREG DONNELLY: Dr Lyons, once again take this on notice if you need to do so. Is it your evidence that the board provided for in the legislation may well be—my words—something that may be costed as a cost that would need to be managed by NSW Health with this legislation in place, but with respect to everything else other than the board, that is, in effect—once again, my words—absorbed within the cost of running NSW Health, as the primary health entity in the State? Is that your evidence?

Dr LYONS: That is the starting position. If, of course, during the course of implementation there are costs where we would argue additional resources are required, there is a process internally for additional support to be accessed within the budget we have.

The Hon. GREG DONNELLY: That is the Health budget?

Dr LYONS: Yes, within the Ministry of Health budget and the budgets that are allocated the respective divisions and branches. So we would go through that process but, of course, where an entity is to be established, which has a series of functions, we would ensure that there is appropriate resourcing for that entity to be able to carry out its functions effectively.

The Hon. GREG DONNELLY: So would it be the case then, based on the evidence you have just given, that on a rolling annual basis it will not be possible to be able to establish what the cost is of operating voluntary assisted dying as a procedure in the State?

Dr LYONS: No more or less than any other aspect of the things that we are responsible for delivering on.

The Hon. GREG DONNELLY: Sure. So we might be able to see what the board costs, perhaps as a figure, if we dig down but, essentially, it will be absorbed within the overall operational running costs of NSW Health.

Dr LYONS: That is correct.

The Hon. GREG DONNELLY: Can I just return, then, to the question we canvassed this morning about the question of consent. It strikes me that nothing is more important, we can all agree, than consent. It is clearly and unequivocally front and centre of our thinking. With respect to the consent provisions of the legislation—the legislation being the bill—clause 6 deals with the issue of decision-making capacity and, in concert with that, you have eligibility criteria in clause 16. There are some others but they are probably the two key ones. From the position of NSW Health—and not putting words in your mouth but just going back to the evidence you gave earlier today—NSW Health has not done its own examination of those provisions in the bill that deal with consent and formed a view about whether they are robust. Is that the case?

Ms O'SHANNESSY: We have not reviewed them in detail, no.

The Hon. GREG DONNELLY: Your earlier evidence was that, as I understand it—and once again I am not being smart—primarily your review work has been the comparative analysis with other States and other jurisdictions. That is what I took from your evidence earlier today. But are you saying—and once again I am not playing here—that you have done some review on this issue of the consent provisions or the provisions in the bill that deal with consent?

Ms O'SHANNESSY: No.

The Hon. GREG DONNELLY: So have you reviewed it?

The Hon. ANTHONY D'ADAM: Point of order: My point of order is on the same basis as Trevor's. Ultimately, the Government is neutral on the bill so they cannot take a position in terms of whether the bill's provisions are robust enough; that is for the Parliament to determine. So questioning the witnesses about any issue of policy is out of order.

The Hon. GREG DONNELLY: To the point of order: The witness has just said that there has been some review about the matters of consent. That was your answer.

Ms O'SHANNESSY: No.

The Hon. GREG DONNELLY: It is perfectly in order, if that was the evidence from the witness, to say, "Can you please elucidate on what you have just said?"—

The CHAIR: I am prepared to rule. The question from Mr Donnelly was in order in that he was asking whether any work had been done. I think he asked for an elucidation confirming whether he was right in his initial interpretation that there was no work done. Further questioning on that issue is, I believe, outside the restrictions that this Committee adopted. Mr Donnelly has asked whether there was any work done as part of the review—

The Hon. GREG DONNELLY: And the witness has said that there has been a review.

The Hon. TREVOR KHAN: No, I do not think that is what the witness has said at all. Her reactions and her body language at the moment indicate that we are at cross-purposes.

The Hon. GREG DONNELLY: Okay, let the witness clarify her position.

Ms O'SHANNESSY: Let me elucidate. We have done a comparison of those laws.

The Hon. GREG DONNELLY: Yes.

Ms O'SHANNESSY: Yes, we have done that. We have not gone and done an analysis of the factors in the decision-making capacity in the bill to take a view on whether we think they are adequate or not, because that is ultimately a policy decision for Parliament to make that call. To be frank, you have had a lot of very eminent people advising and giving evidence on these issues, so I think you are well placed to have a lot of that evidence before you.

The Hon. SCOTT FARLOW: Effectively, a comparison has said that this is the requirement in New South Wales as proposed by this legislation, this is the requirement in Victoria, this is the requirement in Queensland—

Ms O'SHANNESSY: I would have to check because my recollection is that we were trying to figure out the differences in the decision-making process more from an implementation point of view. We will provide that table.

The Hon. GREG DONNELLY: But you have agreed to provide that. That is fine.

Ms O'SHANNESSY: I am not sure it goes into the comparison of how they have looked at consent or capacity.

The CHAIR: With that, unfortunately, our time is an end. I thank our two witnesses for making yourselves available today to come in and providing us the opportunity to ask questions. For the questions you have taken on notice, the secretariat will be in contact to have those tabled.

(The witnesses withdrew.)

(Short adjournment)

CHARLOTTE HESPE, New South Wales and ACT Faculty Chair, Royal Australian College of General Practitioners, before the Committee via videoconference, sworn and examined

CARMELLE PEISAH, Conjoint Professor, University of New South Wales, Clinical Professor, University of Sydney, Founder and President, Capacity Australia, and Member, Royal Australian and New Zealand College of Psychiatrists, before the Committee via videoconference, affirmed and examined

LINDA HANSEN, Chief Executive Officer, Palliative Care NSW, affirmed and examined

THERESE SMEAL, President, Palliative Care NSW, and Senior Palliative Care Clinical Nurse Consultant and Member, Palliative Care Nurses Australia Inc., sworn and examined

The CHAIR: Welcome back to the next session of the hearing. We will now move to opening statements. Does either, or any of you in the room, Ms Smeal or Ms Hansen, have an opening statement?

Ms SMEAL: Yes, I do.

The CHAIR: On behalf of both?

Ms SMEAL: We were going to make an individual one, if that is okay.

The CHAIR: Okay. Ms Smeal, we might start with you, if that is okay.

Ms SMEAL: Okay. Thank you. Thanks for the opportunity to speak here today. As I said earlier, I am representing the Palliative Care Nurses Australia organisation, which is a professional organisation that represents palliative care nurses across Australia, but obviously we are talking about New South Wales here today. I am sure, to define palliative care, it is not a new definition but it is the physical, psychosocial and spiritual care of people who are living and dying with a progressive life-limiting illness. For many years the palliative care context was always connected with the cancer trajectory, and rightly so, but we now know that we are looking after many people also with non-malignant illnesses, such as neurodegenerative disorders, end-stage renal, cardiac and respiratory diseases, and the late side effects of diabetes.

The importance of access to specialist palliative care is extremely important. Whilst we have grown and developed palliative care in this State and have probably been a pioneer in the country around developing specialist palliative care—and that is both multidisciplinary and interdisciplinary—we certainly do not have equitable access. By that I mean that where you live—in Tibooburra, Walgett, Randwick, Mount Druitt or all points in between—there is no consistent access to palliative care. We know that in the last four of five years there have been recent surveys done where at least 60 to 70 per cent of people state that if they were to be dying of a progressive life-limiting illness that their place of choice would be to die at home. Clearly, we do not have the services either in the home setting, in emergency departments [EDs] and of course in many hospitals.

So people, when we talk about informed choice, need to have access to make that informed choice. It is great in the theoretical model but in the real world we are still—and New South Wales has done quite well in the last four or five years in terms of palliative care funding—nowhere near funding what we do need. We know that whilst the GP setting is not a State responsibility, that has to go hand in hand with people deciding to die at home. So the whole concept of dying at home requires 24-hour access to care. It is not just the nine to five. People do not die between the hours of nine to five at home and they do not die nine to five in ED either. So that access, whether it is in a hospital setting or in the home setting is so important. I feel that this debate really does require to fully understand that so that people then, including yourselves, can make informed decisions about what the residents of New South Wales require. It also goes to the point of the education and support of particularly nurses but all health professionals so that all health professionals have at least a primary understanding of what palliative care is, and a big part of palliative care provision is the education and support of carers. If you ask most clinicians they will talk about the fact that it is a 50/50 split of the support and education that is ongoing to carers and families. So I thank the Committee for the opportunity to speak and hope the discussion goes well. Thank you.

The CHAIR: I did not want to interrupt your opening statement but, just in relation to this inquiry itself, it is into the provisions of the bill. So, as much as I have allowed some fairly wide latitude, most of the questions I expect that you will be asked are around the provisions in the bill, not so much around some of the issues that you have raised in the opening statement.

Ms SMEAL: I understand that.

The CHAIR: So I just wanted to foreshadow that so that you would actually understand why the questioning is the way that it is. Ms Hansen, if you would like to make an opening statement?

Ms HANSEN: Yes, and with that in mind I would just like to briefly describe Palliative Care NSW as the peak body in that we represent the palliative care workforce in New South Wales but we also look to provide support and services to the families and carers of New South Wales as well, as a relatively small body, and just support Ms Smeal's statements around the variety of equity of access to palliative care around New South Wales, which I know you are all aware of.

The CHAIR: Thank you very much, Ms Hansen. Associate Professor Hespe, would you like to make an opening statement?

Associate Professor HESPE: Thank you, yes. I will just make a brief summary. Consistent with the national policy and position of the Royal Australian College of GPs, the New South Wales and ACT Faculty is generally supportive of this bill, subject to explicitly precluding acts that do not constitute voluntary assisted dying or assisted suicide, such as withholding or withdrawing medical treatment in contradiction of a person's previously expressed wishes and/or where they can retain capacity and have refused life-sustaining interventions; withholding or withdrawing futile treatment; administering palliative medication with the intention of relieving pain and suffering with the understanding that the treatment may hasten death; and administering terminal or palliative sedation to induce decreased or absent awareness so as to relieve otherwise intractable suffering.

Secondly, but most importantly, it is existing within a framework that actually is first about the dignity, wishes and interests of the dying person, who is at the centre of all decision-making and this prioritises and adequately practices high-quality end of life palliative care services that address the need of all patients at the end of life, not only those who wish to request voluntary assisted dying and that it recognises and supports the role of general practices essential to meeting society's growing need for high-quality end of life care.

The CHAIR: Thank you, Associate Professor Hespe. The Deputy Chair has just asked, are you able to provide your opening statement if you have read it, just so that we can have it for a provision for both Hansard but also for members, if that is possible at all.

Associate Professor HESPE: Certainly.

The CHAIR: Thank you very much. Professor Peisah, could I invite you now to make an opening statement.

Professor PEISAH: Thank you, yes. Good morning. I am speaking both as a stakeholder representative and expert on behalf of both the Royal Australian College of Psychiatrists and the Australian human rights charity Capacity Australia, of which I am a founder and president. I do so because our positions on voluntary assisted dying are aligned and because Capacity Australia has contributed to numerous related such inquiries including the New South Wales Legislative Council inquiry and the Australian Law Reform Commission report on elder abuse as well as being the nominated capacity and decision-making resource for a number of key national bodies such as the Aged Care Quality and Safety Commission. I am also co-author of the major AustLII text *Capacity in the Law*. I would like to inform the Committee that I have submitted several resources to assist the inquiry to which I will refer during my statement and which I request be tabled.

The CHAIR: Absolutely.

Professor PEISAH: Have you received them?

The CHAIR: We have, Professor.

Professor PEISAH: Thank you, good. My first point in my opening statement is that we applaud the considered and thoughtful manner in which the Committee has dealt with the amendments in the consideration in detail, which I have read considerably, and we support many of the stances. In particular we support amendment to part 2, provision 16, conferring ineligibility by virtue of dementia due to the complexity and seriousness of the VAD decision. Secondly, we support negativisation of amendment to part 1, division 3, linking lack of capacity with mental illness while at the same time preserving part 2, provision 16, conferring ineligibility based merely on the presence of mental illness. We, aligned with discussion that is documented in the consideration in detail, make a distinction between eligibility for VAD preserved for people with mental illness provided they have capacity as distinct from eligibility for VAD being provided merely because of mental illness.

Thirdly, we support negativisation of the amendment regarding the actual voluntary dying system substances involved, discussions of which we feel are critical matters not to be legislated. The complication rates discussed are extremely important and part of the role of practitioner and capacity assessments of obtaining consent to ensure that the patient has been provided with relevant information required to make the decision, including such things as you have discussed—treatment failure such as prolonged dying and side effects. By necessity, this detail must be included in the requisite training for practitioners operating under the Act. We have outlined these obligations in the paper that I have provided you, "Biggest decision of them all".

Fourthly, we support the amendment in both part 12 and schedule 1 to reinforce cognitive safeguarding by elaboration of the meaning of pressure or duress, including elder abuse, and by strengthening recommendations for the training in relation to this matter. Again to refer to comments in the consideration in detail, while not suggesting that all older people are vulnerable, we have a special duty to make sure that the interests of those older or other vulnerable people are protected and that there is no suggestion that they might be acting under any duress or elder abuse or other abuse of vulnerable people. We refer the Committee to the papers "Biggest decision of them all" as well as the paper "The Nexus between Elder Abuse, Suicide and Assisted Dying".

Our only residual concerns are threefold. Firstly, we do not think that part 1, division 2, subdivision 4 "Principles" protects old people and people with disability enough. While we applaud the amendment to clause 4 (1) (i) regarding those living in rural and residential areas, we strongly suggest that an additional clause (j) be added regarding residents of both aged care and residential disability facilities having entitlements to the same level of access to high-quality care and treatment, including palliative care and treatment to minimise the person's suffering and maximise the person's quality of life, as persons not residing in such facilities.

We note both the recent Royal Commission into Aged Care Quality and Safety and the follow-up New South Wales Legislative Council inquiry into the provisions of the Public Health Amendment (Registered Nurses in Nursing Homes) Bill 2020 to investigate understaffing and the need for mandated registered nurses in residential care to provide comprehensive care including management of pain and other forms of distress. These inquiries clearly document the deficits in palliative care for older Australians, which for some constitutes elder abuse by neglect with violation of the human right to be protected against abuse, torture and cruel, degrading treatment, as we have stated in our international paper which I have provided you, *The Human Rights of Older People With Mental Health Conditions and Psychosocial Disability to a Good Death and Dying Well*.

As noted in this paper, we also cannot forget the human rights to quality end-of-life care owed to the even more invisible and neglected Australians living with intellectual and physical disabilities in care facilities. From the consideration in detail I can see we are all in agreement that we cannot be providing access to VAD as a solution to inadequate care or in prioritising access to VAD over the human right to access to the highest quality of health care at the end of life and the human right to the relief of pain and suffering. These issues are even more acute now, as you have highlighted in the consideration in detail, in the face of the biggest public health crisis that New South Wales has ever faced.

Our second concern is our disagreement with the negativisation of the amendment to delete part 2, division 16, the reference to the presumption of capacity. We agree with the arguments outlined in the consideration in detail. As experts in capacity in the law that [audio malfunction] the presumption is contradictory to the starting point using the act of this being a rebuttable presumption, appropriately so due to the severe and life-threatening illness faced by patients seeking VAD. Further we agree that this requisite to the presumption of capacity is confusing with [disorder]. Given our empirical research internationally regarding the deficits in doctors' understanding of law and capacity, I can tell you with considerable expertise in this area that the majority of doctors would never have even heard of presumption of capacity. As you have stated in the consideration, to place reference to this common law concept in a bill where the consequences of the decision being made is death when we are given a mandate of actively establishing capacity is both unnecessary and unhelpful.

My final point is that we agree with the concerns expressed in the consideration in detail, as stated, that we ensure that proposals to promote VAD do not undermine efforts to prevent suicide for all, particularly for older people and most so for men over 80 amongst whom have the highest rates of suicide, often due to untreated depression, pain and medical illness despite the ageist assumption that advanced age per se renders life not worth living. Thank you for allowing me to have such a prolonged opening statement.

The CHAIR: Thank you, Professor Peisah. I just need to clarify, we have got a number of titles with which you have appeared today. Can I just confirm, there were a number of references to "we". Under which of your capacities that you are appearing are you referencing the "we"?

Professor PEISAH: All of them. Thank you for that question, and my apologies for my ambiguity. I was going to clarify that because our positions are aligned. The "we" refers to the College of Psychiatrists and Capacity Australia. If in the course of this inquiry you ask me a question of which I will be responding as president of Capacity Australia versus the college, I will make that distinct, but my opening statement represents the position of both the College of Psychiatrists and Capacity Australia.

The CHAIR: Thank you very much for that clarification.

The Hon. GREG DONNELLY: Thank you all for making yourselves available today, those appearing in the room and those remotely. It is greatly appreciated. Can I ask my first questions to the palliative care representatives here today, specifically the Palliative Care Nurses Association Inc. and Palliative Care NSW.

Perhaps we will start with you, Ms Smeal, specifically going to your submission, which is submission No. 71 to the inquiry. Your opening statement made some, dare I say, pretty explicit and clear opinions that you exercised as the representative of the organisation you are here today representing about the state of the availability of palliative care in New South Wales. You made that quite clear I think to everyone around the table—certainly myself. I am wondering, as a starting point, how does your organisation come to the conclusions that you have made today in terms of how you have expressed an explanation of the availability of palliative care in New South Wales? How can you do that? What is your basis for making that claim?

Ms SMEAL: I would say, at an empirical level, that is probably one of the real challenges in the State in terms of very clear data. My account is always probably more anecdotal but it is no doubt very factual. If I look at whether it is a metropolitan area—and there is some level of belief that if you live in metropolitan Sydney, then it is okay around palliative care but once you go regional, rural and remote, it gets tougher. That is not the case these days; there are challenges of access everywhere.

If I could just sort of use the example of someone who is perhaps in the last three months of their life choosing to be at home if possible, we know that for a start there are impositions on people if they are choosing to have their care at home rather than in a hospital setting. Once you are in hospital, of course in our very good public health system it is free to you—you are paying through your Medicare et cetera. Once people come home, and that is where as we know at least 50 per cent to 70 per cent of people want to be, there are impositions just financially for a start.

We discharge someone from a hospital, we talk to them about the fact that there will be a cost for at least the delivery of the equipment that is required. You cannot care for someone dying at home without a baseline of equipment. You do not need a hospital ward full of equipment, but at a very practical sense you need a hospital bed, you may need some toileting requirements if people are still mobile and there are other things you need. That all costs people in most local health districts [LHD], and that is one of the challenges. We are so inconsistent across our LHDs.

The cost of pharmaceuticals—whether we like it or not, many people who are dying of a life-threatening illness do tend to have quite a plethora of medications to manage their physical symptoms. When you are in hospital, they do not cost anything. Once someone comes home, they are therefore then paying for those medications, some of which are not listed on the Pharmaceutical Benefits Scheme. There is the access of even getting medications. If a person has one carer and that carer has the 24-hour responsibility of their spouse, if we use that as an example, they have then also got to be able to get out to their retail pharmacy to gain those medications. Normally it is the palliative care team that ensures that retail pharmacy has access to those medications. There is a myriad of challenges that if we had a more holistic service where a carer did not have to do those things for a start, we could let that carer concentrate on being a carer but not the logistical coordinator of that care at home. Once you go to hospital, carers can be just the spouse, the sister, the mother, whatever. That is the sort of practical examples.

I think the other issue is just that it is a 24-hour burden for carers. Carers take that on willingly and lovingly on the whole, but most services have a fairly nine to five provision and that is just because of what they are funded for. Frankly, as you all know, things do not just happen nine to five. There are some LHDs that perhaps have an extended service from say seven in the morning until nine at night, but again, that is not consistent across the State. For many areas, come six o'clock at night, shops shut. Yes, you may have access to a phone line support service but, frankly, if I am at home looking after my husband, whether I am 45, 75 or whatever, I would probably need a bit more than that to do this successfully to then be able to say people have been provided with every opportunity to then make decisions, whatever they may want to make, rather than perhaps choosing to make decisions because they are not in fact receiving what they should be entitled to.

The Hon. GREG DONNELLY: It is very clear from the opening part of what you just responded to, Ms Smeal, that it is very much being at the coalface of doing this work—that is, palliative care nurses and the specialty of that—that is informing your understanding of this issue about the matter of palliative care in the State.

Ms SMEAL: Yes.

The Hon. GREG DONNELLY: Can I please take you to the bottom of page 1 of your submission. You have touched on it but I think it would be helpful for me to ask you to elucidate. You say:

> In NSW successful community models of care rely on a resourced and accessible Specialist MultiDisciplinary Palliative Care Team working with an adequately resourced Primary Team of nurses and GP's. In some parts of NSW, 40% of their workload is Palliative Care, yet they do not have the capacity to meet current patient needs.

I will take it in parts, first of all, to help me understand. The explanation of what a specialist multidisciplinary palliative care team, what does that mean, as we understand it today?

Ms SMEAL: In a community nursing setting you have a team, dependent upon which local health district [LHD] we are talking about, of a group of specialist palliative care providers. They are people who have got postgraduate qualifications in palliative care—I am talking doctors, nurses and allied health—but they are obviously a small percentage of that workforce who would be looking after the population of that particular LHD. You have to rely on what is called the primary level workforce, which for the home setting would be the generalist community nursing teams and the general practitioner

Those two teams of people are integral to the care of people at home, particularly the GP but definitely the community nurses. In a perfect world every client, the patient, requiring palliative care could be seen by a specialist palliative care nurse but, in fact, they probably do not need that because a lot of what the specialist palliative care teams do is educate the community nurses, the GPs, the local clinical psychologist's practice, whatever it may be, the volunteer services. So that is often their role, as well as being at that clinical coalface providing expert care.

The CHAIR: If you do not mind, Deputy Chair, I will check if any other members have any questions at the moment.

The Hon. SCOTT FARLOW: I am happy for the Deputy Chair to continue.

The CHAIR: The Deputy Chair has the call.

The Hon. GREG DONNELLY: Thank you for that explanation about the team. In terms of the membership of a specialist team and the categories of medical people within that umbrella, just for my own edification, what would that look like in terms of the medically trained professionals, those who have specifically completed a medical degree, and then could you spill on to talking about the nursing, and then beyond that how that might articulate to enrolled nurses and the community network of work done by Ms Hansen's—

The CHAIR: I am going to flag, Deputy Chair, that while I have provided the ability for members to have wide latitude, I am unsure about that question or how it would lead into questions that relate to the provision of the bill.

The Hon. GREG DONNELLY: Mr Chair, can I take you specifically to the bill? I am sure the witnesses have a knowledge of this and may have the bill in front of them—clause 4, principles of the bill, subclause (1) (d) deals specifically with:

> (d) a person approaching the end of life should be provided with high quality care and treatment, including palliative care and treatment, to minimise the person's suffering and maximise the person's quality of life,

That is the overarching principle that emanates throughout the whole bill. And then if we go to—and this is my second example; I can find more if you wish—subclause 10 (2) (c), which deals specifically with "palliative care and treatment options available to the person". That is precisely what I am elucidating from my question.

The CHAIR: While I accept that, I will allow the member to continue, but I will be closely monitoring exactly how we are relating to the terms of reference and the provisions within the bill. I am yet to be convinced that discussing the make-up and training of the teams for palliative care are related to the provisions of the bill.

The Hon. GREG DONNELLY: Are you inviting me to respond to that or are you making a point?

The CHAIR: I am saying I will be monitoring it closely. I am guiding you to direct your questioning in this instance, once you have an answer, towards the provisions of the bill, if you would not mind.

The Hon. GREG DONNELLY: Okay. Perhaps if I preface all of my questions by referring to the principles in the bill? Does that deal with it—specifically for the bill? Because the issue of high-quality care and treatment is a principle in the bill. The issue of who makes up the teams, in terms of the medical specialists and the palliative care nurses, registered nurses and enrolled nurses and the community volunteer network go to this very issue of the provision of high-quality care. That is specifically the point I am seeking to elucidate: What does that mean?

The CHAIR: I have indicated that the question is in order. However, I am foreshadowing that I am keeping a very close eye to ensure that we are abiding by the terms of reference and the principles with which we have been conducting this inquiry to this point. The question is in order. I will allow you to ask it but I would ask you to bring the answers and your further questioning back towards the provisions of the bill. The Deputy Chair has the call.

The Hon. GREG DONNELLY: The position is my question—

The CHAIR: You have the call.

The Hon. GREG DONNELLY: My questions are very specific to the witnesses, all witnesses. They are in complete conformity with respect to the provisions of the bill. I draw your attention to subclause 4 (1) (d). Now I have drawn that to your attention, with respect to the provision of high-quality care and treatment, as expressed in the bill, my line of questioning was about the medical staff, the medically trained, the nurses, the voluntary network. Could you elucidate on what that looks like and how that operates?

Ms SMEAL: Again, I would say it is extremely different right across the State, and therein lies an issue that a resident living in one LHD may, in fact, have access to a team—whether it is a large tertiary hospital as an inpatient or in the community setting—where you will have specialist doctors who have done palliative medicine training, some of whom will be physicians in the first instance and then, therefore, palliative care nurses who, again, have done postgraduate master's in palliative care. Those two positions particularly do a lot of education to all the other providers of care to that palliative care patient. But the challenge relating to the bill around that provision of palliative care that anyone requesting must have had access to is that currently they do not have access. I am talking about the ideal team, but I can also tell you where there is perhaps one specialist palliative care provider, often not a doctor, but a palliative care nurse having responsibility still for a large area where, in fact, those residents cannot possibly have had that access to that quality palliative care.

The Hon. GREG DONNELLY: Thank you for that answer. If I could take that and follow on to a question to Ms Hansen about the work done and the remit of palliative care in New South Wales and the work that it does with respect to the volunteer network that operates to augment and assist the provision of palliative care across the State. Could you provide an explanation of what it is at the moment, how it exists and how it operates as an overview for the Committee?

Ms HANSEN: Sure. Palliative care volunteering exists where there is a service that supports the palliative care network. Palliative care volunteers are recruited usually by a palliative care service or a healthcare provider or an LHD will support a palliative care volunteer manager—a manager of volunteers—to recruit, train and support palliative care volunteers. They have a range of roles depending on who they are supporting, what that person needs and what the interests of the volunteer are. So there is a range of different volunteers across the State.

As for all the other issues around palliative care around the State, each service looks different depending on who is running it and whether there is any funding for it. Volunteers are there to support the palliative care team with the provision of some of their expertise but mostly it is time—so spending time with families and carers and the person who is dying in whatever setting that is; that can be in hospital or it can be at home. So, as with the other issues, the access to volunteers is a huge benefit to every palliative care service where those volunteers exist. So the gaps are where there is no palliative care volunteer service and that is because there is no person funded to run that volunteer service.

The Hon. GREG DONNELLY: And as we move away from the large population centres—and, for convenience sake, we will say Newcastle, Sydney, Wollongong—could you provide please to the Committee an overview of, first of all, the level and the size of the network and the challenges associated with operating as a volunteer network away from the large population centres, particularly in the remote parts of the State?

Ms HANSEN: In some areas it is easier sometimes to run a service in rural and remote areas because the communities are very close and everybody knows everybody within the 20,000-kilometre radius of some of those services. But there are thousands of palliative care volunteers across the State and it has been a really serious impact on their ability to provide service over COVID just for health and safety reasons. But there are no services in some areas, no palliative care volunteers at all, just because there is no funded volunteer manager. And it does not really matter whether it is Broken Hill or on the Murrumbidgee somewhere, it does not matter where it is, if there is some kind of focus on the importance—people providing health services generally understand the importance of the role of volunteers and there is generally a volunteer manager funded and supported to recruit and manage those volunteers.

These volunteers are very carefully selected, I should say. They have to go through—they are usually a bereaved person; it is usually somebody who wants to give back to their community and give back to the palliative care service that supported their person who died. There are rules about the length of time that person has had to be bereaved, because a lot of people just want to charge in there and get straight into it, and really they need to be given time to deal with their grief and bereavement. There are rules about the type of person that might be appropriate for palliative care—this is a quite different area of volunteering to anything else—for their sake as well as the persons that they are going to be caring for and the different families that they go into.

Bear in mind these volunteers are helping a team look after someone who is going to die. So they can get close to people, they get close to the families, they get close to the person who is going to die; they have to be a kind of person who can manage that and deal with that, and they are always supported to do that. So it is quite a different role. Some people, I think, often misunderstand palliative care volunteering as being sitting with somebody and holding their hand. It is very much more than that.

The CHAIR: I am just going to take this opportunity to ask Associate Professor Hespe and Professor Peisah in turn, we have heard from NSW Health this morning that with changes in legislation and policy that are typically large and complex, as the potential introduction of VAD legislation would be if it passes the Parliament, a number of health sectors would look to NSW Health and their policies and guidelines that they develop. Are you able to provide some insight as to how a private GP or perhaps psychiatrist might look to the guidelines and policies of NSW Health in developing how they formulate their work and provision of any VAD on the work that is done by NSW Health? I will start with you, Associate Professor, if that is all right, and then I will go to Professor Peisah.

Associate Professor HESPE: Thank you for that question. Can I just point out that for all GPs we work across all of Australia under the terms of Medicare, so therefore in terms of GPs they are not constrained to just New South Wales in terms of guidelines et cetera and voluntary assisted dying has been introduced for GPs in other States already, with Western Australia and Victoria being particularly large in terms of the GP environment. So, as a result, GPs have actually been very well educated and across the issues that have been rolled out with changes in legislation for voluntary assisted dying. So there has been a lot of education to GPs about what this means, in particular about the ability for them not to be in any way involved if that does not align with their own ethical stance, at the same time as making sure that they actually deliver high-quality care for the patients in front of them.

I just wanted to go back to the previous question, which I did not have an opportunity to put in for. It is really important to know that the services that each individual patient accesses is very individual. It will depend upon their own GP, their own specialty team, what the actual illness is that means that they do not expect to live over the next 12 months, and it is very difficult to put one individual within a formula out there for everybody. I would just be very mindful of that. That is where, from my position, GPs are very good at being able to help people in terms of decision-making and understand what services they might need to get, knowing that access to services, not just in the rural setting, can I say, but also in an urban setting, can sometimes be extraordinarily difficult to access. I think we sometimes forget the very vulnerable population in cities who also have great difficulty accessing appropriate services and because they are not in a rural setting, then there sometimes is not an advocate for them to get the appropriate access to services.

Back to the alignment with New South Wales, for general practices we have a thing called HealthPathways, which is absolutely fantastic, can I say. It is about making sure that GPs know exactly what the evidence is about what they do, how it aligns with the legal framework and accesses to appropriate documentation for wherever it is that they absolutely are. And so this is one of those particular cases where for GPs who may not otherwise know there will be access to a very clear set of guidelines around what are the legal requirements, what the guidelines are, which would link to the current documentation from NSW Health as well as the national guidelines for them, and assistance in terms of accessing the required education, if that is what they would like to do, noting that I do not think any doctor should be part of this process unless they have actually fulfilled the requirements of the education package.

The CHAIR: Thank you for that, Associate Professor. Before I pass to Professor Peisah, I am just going to foreshadow that I will come back to you with a question around GPs and specialist care, if that is all right, because you have just touched on something that I want to come back to. Professor Peisah, are you able to provide a response in relation to the college of psychiatrists?

Professor PEISAH: Yes. In relation to training and guidelines with respect to the Ministry of Health, which I understood to be the first question, as the person who has consulted for education and training regarding the Victorian legislation by the primary providers of that legislation, which was the Queensland University of Technology team of Professor Ben White and Lindy Willmott, there is absolutely no need to reinvent the wheel, but, rather, there is already a template for a substantial and validated and evidence-based training around voluntary assisted dying. In fact, the paper that I have asked to be tabled, *Biggest decision of them all*, which I co-wrote with Professor Ben White, was actually written specifically with the purpose in mind of educating practitioners about the assessment of capacity. So I strongly suggest that you revert to existing education, mindful of the jurisdictional variations in the legislation—and, of course, it would have to be adapted and tweaked in relation to specific New South Wales legislation, but the general principles still apply.

The CHAIR: Thank you very much. We have got that paper here, and we will make sure that that is tabled with our papers when we have completed the hearing.

Professor PEISAH: May I take on notice some kind of reference or to the link or to the description of the existing education that Queensland University of Technology does provide? They provide an extensive end-of-life law education, but they also provide specific education around the Victoria legislation.

The CHAIR: To aid that, Professor, I will ask you if you could provide a link to the training and the items that you have just identified from the Queensland University of Technology. It sounds like you are happy to take that question on notice.

Professor PEISAH: Yes, please, I would like to.

The CHAIR: Associate Professor Hespe, I want to come back to something you touched on around the palliative care issue with GPs, noting that, as I have said, we have got a bit of wide latitude and it has been discussed openly this morning between the Deputy Chair and our witnesses in the room. There is much talk about who makes up the team. I note that you started to touch on the importance of local GPs and doctors with knowledge of their patients in that palliative care and end-of-life treatment. There is a lot of talk about the requirement to be a specialist palliative care doctor. In your opinion, your members, GPs, out in remote, rural areas—are they providing adequate, first-class palliative care to the people they are looking after? Is there any difference in the care they are getting from their family GP or the GPs who are looking after them compared to what they might get with a specialist palliative care doctor?

Associate Professor HESPE: That was a highly controversial way of wording that question, can I say?

The CHAIR: That's me.

The Hon. SCOTT FARLOW: That's Wes.

Associate Professor HESPE: The first thing that needs to be clarified is that GPs are actually specialists. There are still doctors who are practising in the specialty of general practice who are not specialists, but general practice is actually a specialty under the medical board registration. So we need to be very clear, when you use the term "specialist", that GPs with a fellowship are actually regarded as a specialist. So that is point one. Point two is that there is also then the added rural generalism or remote medicine specialisation that some GPs will also have who actually do practise general practice in a remote environment. They are not required to have the extra specialist qualifications for remote and rural, but they can do. They can get that both through the college of rural and remote or through the college of GPs.

Both of them give equal level qualification to being—there are a few different terminologies around it, but the term for actual "rural generalism" is coined by many. If you actually do that specialty, then it will depend upon what they actually specialised—which emphasis. They have to do two extra streams of training. Some will do obstetrics and gynaecology, some will do palliative care, some will do anaesthetics et cetera, so there are a number of different themes. Again, just that qualification does not necessarily say what extra training they may have done. So that is point number two.

Point number three is that there are an awful lot of GPs who are specialist GPs who have done palliative care as an extra stream of training anyway. So someone like myself—I have done extra training in obstetrics and gynaecology, I have done extra training in paediatrics, I have done extra training in palliative care and I have done extra training in dermatology, but you do not necessarily see that in my fellowship as a title, okay? But they will have done a level of diploma et cetera. So if we are talking about what different GPs can offer, there are an awful lot of GPs who do do palliative care as an offering. So my practice, for instance, takes referrals from the local palliative care team to actually manage patients in the community, as a partner of the palliative care team, to oversee the care that is delivered until actually that patient dies. Not all practices do that, so you cannot—again, it is always that difficulty about what different people can access. So your own GP may or may not do that, but that GP can hand their care over.

If you are talking about what level of care they get, I would hope that if you have a GP who knows you then you obviously should be able to access all of the care that you need at any time, and there should be no difference in the quality of care, knowing that that is coming from a—if I am pragmatic, I understand that not all patients access the quality of care that I would espouse everybody to be able to access. That is due to a number of access and affordability criteria, particularly—if I want to get onto my hobbyhorse, it is about the defunding of primary care services, which has, unfortunately, been a body of good work being done from high levels of finance for the last 15 years in particular, where the sustainability of the provision of good-quality primary care services has been totally destabilised because it is no longer financially sustainable under the current Medicare model. But that aside, the GPs are trained and there usually is someone that you can do. Now with telehealth, can I say, it makes the ability to have the right person being consulted and being able to provide the services much, much better for some of the more remote issues, not taking into that account, obviously, the issue about access to the telehealth portal that you might use, whether that be a video platform or, less optimally, phone.

The CHAIR: I have one more question before I pass back to the Deputy Chair to continue his line of questioning. Associate Professor, for people who are in their end stage of life and are about to receive palliative care, how important is it, for example, that it is their GP who will be providing that palliative care support to them? How important is it that the patient has confidence that that GP is able to provide them that care? Do you think that that perhaps could be slightly eroded by the discussion around whether it is a specialist palliative care doctor who they are seeing as opposed to a GP, and do you think that eroding of confidence is perhaps, in a way, unhelpful to the patient?

Associate Professor HESPE: Thank you for that question. I think that is a really good way of actually approaching this issue. From my perspective, the GP is absolutely key in assisting a patient to navigate the pathway of treatment that they need to access. Whether that GP is the person who actually provides the palliative care services or not does not take away from the most important person that patient has to be able to discuss what it looks like being able to continue to be in their care. It actually comes back to how we actually support team care, shared care and—what gets talked about a lot—integrated care.

But really it is about having really good communication portals and a good communication mechanism between the GP who might know that patient to be able to be an advocate for them about the services that they get from a specialty palliative care service being appropriate for them culturally, with a background of their other sort of stuff that might be part and parcel of their mental health, previous health issues et cetera. So rather than it eroding, I think it is very important to actually understand the role of the GP, who does not need to be the palliative care person but still needs to be part of the palliative care service provision for that patient. Does that make sense to you?

The CHAIR: It absolutely does. Thank you very much for that. I will pass to the Deputy Chair.

The Hon. GREG DONNELLY: Can I ask Associate Professor Hespe a direct question. I do not wish to be taken the wrong way, but you are here today representing the Royal Australian and New Zealand College of General Practitioners.

Associate Professor HESPE: No, just the Australian, not New Zealand. We are the Royal Australian College of General Practitioners.

The Hon. GREG DONNELLY: Okay. I am reading from the document placed in front of me by the Parliament, so I withdraw that. Is it the New South Wales/Australian Capital Territory division or branch?

Associate Professor HESPE: We are a national organisation. The psychiatrists are Australia and New Zealand, so that may be where some of the confusion arose. We are the Royal Australian College of General Practitioners, and I am the head of the New South Wales and Australian Capital Territory faculty. But we are one national organisation.

The Hon. GREG DONNELLY: Thank you very much. I am wondering why a submission was not made to this inquiry by your organisation.

Associate Professor HESPE: That is a good question. I think it is because we have just had a changeover of management and because we are a national organisation it went to national and slipped under the radar. That is one of the difficulties when you have a national organisation and you have multiple States bringing in—

The Hon. GREG DONNELLY: That is fine; I accept your explanation. I am not reflecting on you. You would be aware that various other professional health bodies have made submissions to the inquiry. You would know that, would you not?

Associate Professor HESPE: Yes. Obviously, I became aware when it came in. Nobody actually notified me that there had been a request.

The Hon. GREG DONNELLY: That is okay. Have you had an opportunity to read the submissions from some of those other medical bodies?

Associate Professor HESPE: No.

The Hon. GREG DONNELLY: So I gather you would not be aware that a number of them have made some explicit recommendations in their submissions about some proposed amendments to the legislation that has been proposed to deal with some of their concerns. You would not know that.

Associate Professor HESPE: I would not know what they look like, no.

The Hon. GREG DONNELLY: For example, we heard form the Australian Medical Association NSW this morning and they made a detailed submission. They have raised a series of issues and concerns that they have with respect to the legislation. In fact, they have gone a step further by proposing the wording of amendments in some cases to ameliorate some of their concerns. Does that organisation cover GPs?

Associate Professor HESPE: Yes, that is right. But they have members—they are like the union versus the college.

The Hon. GREG DONNELLY: Right. That is an important distinction, I suppose. With respect to the college, which is the professional body—is that the terminology that you are comfortable with?

Associate Professor HESPE: Yes.

The Hon. GREG DONNELLY: So with respect to the college—this is the principal college for general practitioners—you have no particular views about any amendments that could be made to the proposed legislation to improve it, enhance it or make it a better piece of proposed legislation?

Associate Professor HESPE: As I have said, we are very mindful about the legislation that is already rolled out in other States and the wording of that and the numbers and how it has affected GPs. The numbers have been quite small. We have been as comfortable as you can be that those current frameworks have worked with due care, noting the concerns that I have read in terms of explicitly making sure that palliative care is appropriately offered and high-quality palliative care is part and parcel of any patient's care before they would need to be having a conversation about voluntary assisted dying. From my perspective—and that of my members—if appropriate palliative care was offered then voluntary assisted dying would hopefully not actually be that relevant to very many patients at all.

The Hon. GREG DONNELLY: On that very point about the availability and provision of palliative care, does the college have a view or a position—or could you provide us on notice with a view or position—about the state of the availability of palliative care in New South Wales?

Associate Professor HESPE: Do we have a statement?

The Hon. GREG DONNELLY: Not a statement in words necessarily, but can you give an assessment to us? Because what logically follows from what you have just said, Associate Professor, is pretty significant. It seems to me that one can only really move forward, potentially, of thinking about voluntary assisted dying—this could be an argument, of course, and there are issues around it—if there is the ready availability of high-quality palliative care around the State. Indeed, I draw to your attention a specific provision in the bill. I presume you have had a look at the bill?

Associate Professor HESPE: Yes, and that is what gives me reassurance that the bill does have that as part of it.

The Hon. GREG DONNELLY: Just to be clear, with respect to the bill, the specific reference that is perhaps the most significant about palliative care sits as a principle of the bill. Do you understand that?

Associate Professor HESPE: Yes.

The Hon. GREG DONNELLY: And you understand that a principle is not definitive, per se, in the actual requirement to provide palliative care, is it?

Associate Professor HESPE: Well, we can get into all sorts of pedantics around it but, in terms of patient choice and options for what they know and understand to be able to access, you have to have a service for a person to access and to know and understand what it means. I have certainly found that a lot of patients do not understand the difference between voluntary assisted dying and access to palliative care. Often it is about guiding them down the pathway and understanding in terms of health literacy and what I call "health activation". It is about understanding what it is you are talking about. The vast majority of the time having access to appropriate palliative care services is what people want, rather than access to voluntary assisted dying.

From my perspective, that is where the conversation with a GP is key, because a lot of people do not actually understand it. There are also a lot of specialists, particularly in cancer services, who do not like talking about palliative care because they see it as a failure of their service provision rather than seeing it as part of what I call the whole spectrum of care. We are all going to die so we all need to understand at what point we talk about the service that we are getting as part and parcel of our end of life versus that it will get rid of or cure a condition.

The Hon. GREG DONNELLY: Yes, indeed. So your evidence would be that the general literacy in the community presently with respect to palliative care is quite modest. Would that be your evidence?

Associate Professor HESPE: Yes. There is a lot of conversation around core provision of services and so people may not understand what options they do have and how they ensure it actually meets their needs or those of the person they are caring for.

The Hon. GREG DONNELLY: You have no doubt been following quite closely the inquiry being undertaken by the New South Wales Parliament into the provision of healthcare services and outcomes in regional, rural and remote New South Wales. That would be the case, would it not?

Associate Professor HESPE: Yes.

The Hon. GREG DONNELLY: In your capacity as representing the college, you would no doubt have been following it closely and presumably reading the *Hansard*. You would have seen that in many places we visited we had witnesses come along and explain that in their local communities there are not even general practitioners in towns to provide basic GP health care in many parts of regional and rural Australia. You would know that, would you not?

Associate Professor HESPE: Yes. It is part of a very big advocacy conversation that the Royal Australian College of General Practitioners is having at both a Federal and State level about possible solutions to how we deal with those issues.

The Hon. GREG DONNELLY: My raising this is no reflection on the college; I am sure they are advocating as hard as they possibly can, no doubt along with the AMA. But my question that follows directly from that point is this: If there is no GP in town at all, how is it possible for these discussions around palliative care, as you have articulated so well, to be engaged with in any meaningful way with a person who might have an end-of-life or terminal condition? If there is no doctor in town, how can that be undertaken?

Associate Professor HESPE: It is a bit more complex than just saying whether there is a GP in town or not. There are a lot of different services and ways in which people access certain services. I understand the premise on which you base that, but most people would be able to have access to a GP to have a conversation with. As I say, the good news about COVID has been the access for GPs to telehealth. We just had an announcement this morning, which has been received very well by the GP community, that telehealth will be funded in an ongoing fashion from the end of this year because it does actually mean that we can access people who are in remote areas with appropriate health care with a good GP, who may not be in the same geographical location as you at this point in time. It might not be ideal but, you know, it is about actually having access to the services and the right person to talk to.

The Hon. GREG DONNELLY: On that very point, now I may direct my question to Professor Peisah, who is giving evidence remotely. Doctor, in your submission from the Royal Australian and New Zealand College of Psychiatrists—and thank you for the helpful submission—can I take you to page 5 of that submission, if you have it is and if it is accessible. I invite you to go to page 5 specifically. About halfway down the page you make the following statement—or the organisation makes the following statement:

> Funding for properly developed palliative care services must be provided prior to the introduction of VAD, in order to provide an equitable alternative to people suffering with a terminal illness.

It goes on to say:

> Without adequate resourcing of, and access to, palliative care, VAD legislation, arguably, presents a perverse incentive for patients to choose to end their life, instead of being offered adequate palliative care. The RANZCP has concerns regarding funding of a VAD scheme at the expense of making improvements to other end-of-life care options for Australians.

My first question to you, Doctor, is that that paragraph was put in there quite deliberately and clearly by the college. That has application to the State of New South Wales, which is the remit of this inquiry?

Professor PEISAH: That has application to the State of New South Wales, to the whole of Australia and in fact globally, as we have evidenced by the submission, my opening statement and the papers that I have submitted to you.

The Hon. GREG DONNELLY: So the words speak for themselves. It seems to me that they are very clear. With respect, if I could, I will move onto the next point, which is point number 8, and which is separate but related. There can be a drawing of an issue here, a connectivity, about VAD and people with a disability—a class of individuals that we have heard precious little from, I have to say, as a voice in this inquiry. Have you been following this inquiry, by the way, Doctor?

The Hon. TREVOR KHAN: Well, they have made a submission, Greg. You should make that clear.

Professor PEISAH: Not in detail, sir.

The Hon. GREG DONNELLY: Okay. That is fine.

Professor PEISAH: The principles, I understand. I read the consideration in detail and I know the original Act and I know the amendments, but, sir, I have not followed in detail the written submissions.

The Hon. GREG DONNELLY: That is okay. Well, perhaps I can draw your attention to the Bar Association of New South Wales' submission. I do not expect you to be able to access it readily, but they make some specific comment about the matter of disability and voluntary assisted dying. Perhaps I will draw your attention to it to look at it at a later time, but I gather from your point number 8 in your submission on page 5 you are singling out a particular concern about a class of person and VAD. That is what you are doing, are you not?

Professor PEISAH: I reiterate that in the opening statement. Certainly the work we are doing both nationally and internationally about equitable access to end-of-life care, not only to people in residential care with disability, people with dementia, but in particular people with intellectual and physical disabilities at the end of life. We address that in the paper I have provided you—

The Hon. GREG DONNELLY: Yes.

Professor PEISAH: —about human rights. Actually it specifically refers to that issue with a number of publications documented internationally. There is no question that there is empirical evidence about the neglect of people with disability at the end of life.

The CHAIR: I am sorry, Deputy Chair; I note that we have only 15 minutes left. Seeing as how the Deputy Chair and I have had the lion's share of the questioning, I just want to make sure that all the other members have an opportunity to ask questions, if they felt that they want to address some points. Mr D'Adam?

The Hon. ANTHONY D'ADAM: Yes. I just might come back to this paragraph that my colleague the Hon. Greg Donnelly referred to about an assertion around providing a perverse incentive for accessing voluntary assisted dying. From the Victorian experience, is there any evidence that this is occurring? Can you cite any evidence, Associate Professor—I am sorry, Professor Peisah?

Professor PEISAH: I am not aware. I have not read in detail the analysis of the Victorian legislation and I am not aware of this happening from the Victorian legislation. I speak now with expertise of 30 years providing end-of-life care as a psychiatrist for older people specifically in nursing homes, and as well as academic expertise in this area.

The Hon. ANTHONY D'ADAM: But there is no evidence from our Victorian experience that this is operating as you assert, is there?

Professor PEISAH: I am not aware of it, no.

The Hon. GREG DONNELLY: I have a follow-up question.

The CHAIR: I will leave that as a follow-up question and then I will go around. Just before I do, actually, can I get an indication from any of the other members if they have any questions?

The Hon. SCOTT FARLOW: I have a couple, but I will let Mr Donnelly do it.

The CHAIR: I will allow the Deputy Chair to ask his question and then I will pass to Mr Farlow.

The Hon. GREG DONNELLY: Sorry, Professor. I was referring to you as "Doctor" earlier. I apologise, Professor.

Professor PEISAH: That is all right. I am a doctor as well as a professor.

The Hon. GREG DONNELLY: I am sure you are both.

The Hon. TREVOR KHAN: That has been a matter of some contention last week.

The Hon. ANTHONY D'ADAM: That is right. Better not get it wrong.

The Hon. TREVOR KHAN: We won't make that mistake again.

The Hon. GREG DONNELLY: It is a bit of an insider position because we actually had some debate last week about titles.

The Hon. TREVOR KHAN: Yes.

The Hon. SCOTT FARLOW: It was also about pronouns.

The Hon. GREG DONNELLY: Yes, it is about pronouns, I suppose, and that has nothing to do with you. But just off the back of what my colleague has just questioned you about—about the "evidence" from Victoria—you would be aware, though, first of all, the Victorian law has been operational for about two years or perhaps a bit over two years. Within the collection of information that is mandatory—this is under the Victorian legislation—are you aware that there is a mandatory field to catch information or select information, dare I say, with respect to the possibility of this scenario whereby, without providing resourcing, you could end up with this perverse incentive? Would you be aware that that is a field of information that is caught?

Professor PEISAH: I am not aware of this field but I think that is an important safeguarding approach.

The Hon. GREG DONNELLY: That is fine. Perhaps we ourselves can establish that and perhaps invite you to have a look to see if that is a field of information that is caught. Because if it is not captured—and to the best of my knowledge that information is not captured by the reportage in Victoria—there would in fact be no way to establish whether or not the situation that has been discussed in your paragraph can be reasonably assessed, could there? Information about the perverse incentive, if that is not being collected actively by the Victorian Government through VicHealth and the provisions of the legislation about reportage, how could anyone possibly know one way or the other? Is that not the correct position, if the information is not being collected about the perverse incentive?

Professor PEISAH: Sorry, good question, a very complex question. The question needs to be asked. My concerns are that whether such a question on a tick box actually addresses and excludes such occurrences.

The Hon. GREG DONNELLY: Sure. That is okay.

Professor PEISAH: As a researcher in this area, the issues addressed by Associate Professor Hespe I would totally reiterate. Everything she has given evidence about I would totally reiterate. So I am not sure. Yes, I think that is very complex for me. I do not think I could answer that, whether a question, a tick, whether this perverse incentive has operated or not would actually preclude whether it did in fact—

The Hon. TREVOR KHAN: Could I ask a question that flows from that?

Professor PEISAH: May I just add that as Associate Professor Hespe has said, as a psychiatrist working in end-of-life experiences, particularly for older people in nursing homes, I too have been asked inappropriately for requests to end people's lives in the context of extreme suffering, with untreated end-of-life suffering and inadequate access to good quality end-of-life palliative care. So I would just echo everything Associate Professor Hespe said.

The CHAIR: The Hon. Trevor Khan is seeking an elucidation and then I will pass to the Hon. Scott Farlow to ask questions.

The Hon. TREVOR KHAN: Professor, just on this question of the tick-a-box, when a coordinating practitioner and another practitioner are dealing with a patient who is seeking access to VAD, what they are doing, are they not, is—I do not seek to use the word "only"—assessing the capacity of the patient, determining whether the patient is going to die within a specified period of time and explaining to the patient their various alternatives. That is essentially the task that is put to the practitioners that are involved, is it not?

Professor PEISAH: In a general sense, but it depends on the legislative requirements.

The Hon. TREVOR KHAN: Of course. But what they had in that circumstance hopefully—and indeed it is what they are assessing—is a voluntary patient who is in extremis. That is regrettably the circumstance that the find themselves in, is it not?

Professor PEISAH: A voluntary patient in extremis who has been provided with maximal access to palliative care. A voluntary competent patient in extremis who has been provided with adequate, equitable access to quality end-of-life palliative care.

The Hon. TREVOR KHAN: Yes. I am not doubting anything that you are saying and I am not trying to be tricky. But, for instance, we have received evidence from a Ms Fleming, a nurse, who talked in terms of her experience. And the reality is, isn't it, that even with the best of palliative care, some patients suffer unfortunately untreatable pain and experience all forms of suffering?

Professor PEISAH: Absolutely, over and above adequate provision of palliative care. And in fact that would be the role of the practitioner—for which patients there remains untreatable suffering, who is a competent voluntary patient, where there is suffering for which maximal service has been provided. Absolutely, and they are the candidates. That is what we would seek would be ideal candidates for VAD. I think that is what Professor Hespe, if I may clarify with you, if that is what you are saying, that that would filter down to what is left over, the small minority of patients, which I imagine—again my apologies, I have not looked at the detail [inaudible] and I know there has been analysis—

The Hon. TREVOR KHAN: No need to apologise, Professor.

Professor PEISAH: But I would imagine, so far to date, that has been what has been the experience, I hope, with the Victorian legislation—that small handful of patients who are competent, who are providing consent, who are suffering from a life-threatening illness within 12 months and who have been adequately provided with palliative care. That is the kernel of people that you really want to be providing VAD for.

The Hon. TREVOR KHAN: Sure. And in that context the bill as drawn, can I suggest you, meets that criteria of helping that quite discrete group of patients.

Professor PEISAH: Not in relation to, as I pointed out in my opening statement and our college submission, in regards to patients in residential care. I do not think that the principles of the bill cover patients in residential care. There is no debate about that issue anywhere and I think that does not cover their interests sufficiently. But notwithstanding that, I think it does.

The Hon. SCOTT FARLOW: My questions will be directed again to you, Professor Peisah. I apologise for keeping you on the clock. With respect to your submission and the comments you made in terms of excluding dementia from neurodegenerative diseases, is that something that is done in other jurisdictions' VAD legislation that is around at the moment?

Professor PEISAH: I am not aware. What concerns us at the college and myself as a subject matter expert is that my understanding from the original Victorian legislation is that the neurodegenerative diseases, or may have asked for in the original legislation, was for motor neurone disease. The issue around dementia, which is in fact a neurodegenerative disease, is that the complexity of the VAD decision, as defined in our paper, makes decisions, which is the biggest decision of them all, using the Commonwealth threshold concept of capacity would be the hardest decision to make, but it would be precluded by a diagnosis of dementia.

I am speaking as an international expert in this area, but I would have the backing of my colleagues around the world. Because of the complexity that has arisen in the Netherlands and Belgium on issues around dementia around voluntary assisted dying, the nature of the complexity of the decision for voluntary assisted dying renders dementia as a diagnosis and not an appropriate neurodegenerative disorder that would render eligibility for VAD. That is the position of the college and myself as president of Capacity Australia.

The Hon. GREG DONNELLY: Returning to the witnesses from Palliative Care Nurses Australia and Palliative Care NSW, I have got some other questions but time has run out and so I will probably submit them as supplementary questions. I invite both organisations to make a response to this. If you want more time to respond, you can take it on notice. We have heard much of the provision of care or care that would be available or would be provided—that is the intention by general practitioners—in the event of the legislation coming into being in New South Wales. That has been ably discussed today about what that would look like.

My question to you both is, you obviously have some dealings on a regular basis with people who are involved in working with GPs, or in fact you may be working with GPs and have observed a lot through your respective experiences. But there is this very important matter of decision-making properly understood under the legislation to make a decision around whether a person wishes to go down the path of voluntary assisted dying and this significant matter in play about coercion and what coercion might be, what it might look like or might not look like, as the case may be. There is no disagreement that no-one believes that there should be any coercion associated with that decision. It would turn the whole act upside down and it would be no longer voluntary.

I am wondering from your own respective experiences as organisations whether you could quickly comment on the matter of the challenges that may exist or do exist with respect to identification of coercion or potential coercion of an individual making a decision, particularly a person at the end of life or perhaps a person who may not have all their faculties or may be suffering enormous pain et cetera and the possibility of coercion and the possibility of that happening. It would be helpful to inform us about what your experiences are.

Ms SMEAL: I would say as a clinician of 35 years in palliative care that I have not seen evidence of that level of coercion at all to be honest. I think what I see at times is the desperation of a person living with a life-limiting illness and the distress they believe that the care they require from often a single carer is enormous. I do not think in reading the bill that would be defined as coercion at all, and I only have a small avenue within the dementia area so I am not going to comment on that particularly. But I do not see that coercion in my practice, particularly over many years. Of course that has been without the context of a looming VAD bill. It is something that I think all health staff now need to have some healthy understanding of to in fact reflect on what they may or may not observe in the future.

The Hon. GREG DONNELLY: Might that go to questions of defining what that is or could look like?

The CHAIR: I invite the Deputy Chair to put those on notice because we are already over time.

The Hon. GREG DONNELLY: Did Ms Hansen want to quickly answer?

Ms HANSEN: For me, it is about providing better support and education ongoing for GPs. It in fact goes to education, right from undergraduate education about end-of-life care communication and training—pardon me, I might have to stop there, sorry.

The Hon. GREG DONNELLY: Take a sip of water.

The CHAIR: You take a drink. We are out of time, and I am sure the Deputy Chair can put more questions to you on notice if required. For those witnesses who have taken questions on notice, the secretariat will be in contact with you to table those answers. I thank all the witnesses for appearing today.

(The witnesses withdrew.)

(Luncheon adjournment)

CRIS ABBU, Policy and Projects Manager, PM Glynn Institute, Australian Catholic University, sworn and examined

MICHAEL CASEY, Director, PM Glynn Institute, Australian Catholic University, sworn and examined

JOHN FLEMING, Retired academic, Former President of Campion College Australia, before the Committee via videoconference, sworn and examined

The CHAIR: Welcome to the afternoon session of the hearing today. I welcome our witnesses. We will move to opening statements. Do the witnesses in the room have a statement each or are you combining your statements?

Dr CASEY: I think we both have a statement.

The CHAIR: Wonderful. I will start with Dr Abbu.

Dr ABBU: Around a month ago we did a study on access inequity of palliative care in regional and remote New South Wales. We wanted to look at equity and access. In doing so we analysed one of the primary considerations of access inequity, which is the workforce. Our underlying question was: Were there any palliative care services in regional New South Wales? We looked at trend data from 2013 to 2020, which is seven years. That is important to take note of because we did not just do a one-shot, single-year analysis. There were significant findings, which we have written in our submission to you. Foremost of this was while the number of palliative care doctors have increased through the years in the cities, in the regional areas—particularly the outer and remote regions—in those years, from 2013 to 2020, there were no palliative care services in most years. There were only two years, 2017 and 2015, which had around three in the outer regions, but the remote regions had nothing.

In the cities the number of palliative care doctors, in fact, increased from 68 palliative care physicians in 2013 to 100 in 2020. So, in fact, the bulk of palliative care doctors were in the cities—more than 90 per cent were in the cities. This alludes to what the AMA—the Australian Medical Association—had said, that the absence of such service delivery has resulted in some very poor and sad outcomes for those in regional and remote New South Wales. The second point that we made in that report was that while palliative care doctors in the cities work the standard hours of 35 to 40 hours a week on average, those in the regions— although a very small number—work for up to 70 hours a week on average.

They were older too. If you look at age categories, they were female and much older than those in the cities. Why is this important? This is consistent with what we had found out when we looked at the national situation with palliative care services in our report that was published earlier this year. We said there that these doctors are getting old and they had said that around 42 per cent of them are planning to retire in the next 10 years. The implication is really on the absence of such services plus the continuity plan, the succession plan, when these doctors retire.

The same situation is with the nurses as well. In major cities we have many, from 568 in 2013 to 649 in 2020. But in outer and remote regions—for outer regions there were only from two to 45 palliative care nurses. For remote regions there was really none. We looked at this in this context: Is there a gap in provisions? Is there an absence in provision? Clearly there was in those years, from 2013 to 2020. Our position is that these gaps must be addressed first and foremost before considering VAD.

The CHAIR: Thank you, Dr Abbu. Dr Casey?

Dr CASEY: Thank you for the opportunity to give evidence today. In the covering letter to my submission I set out a public policy proposition. The proposition is that before a community decides to take a momentous step such as legalising assisted dying, governments and lawmakers should ensure that everything possible has been done to address the significant inequities in the provision of palliative care and in access to it. As you know, our submission includes an analysis of workforce trends for palliative care doctors and nurses in New South Wales, about which Dr Abbu has just spoken. This analysis highlights workforce shortages in palliative care, which means, of course, significant inequities in the provision of palliative care and in access to it, particularly for people living in outer, regional and remote areas of the State. The proposition that before contemplating the legalisation of euthanasia and assisted suicide we should focus our energy and resources on doing everything possible to ensure access to high-quality palliative care for everyone who needs it, irrespective of where they live, is based primarily on the momentous changes which the legalisation of euthanasia entails for our shared values and for both the function of our laws and the practice of health care.

The nature of these changes is perhaps encapsulated in part 9 of the Voluntary Assisted Dying Bill. These clauses provide protections from criminal and civil liability and from any sanction under the professional conduct principles for health practitioners and other people who, in good faith and in accordance with the provisions of the bill, provide assistance to people in accessing assisted dying. These protections extend to ambulance officers and other qualified people who do not administer life-saving treatment to someone who is dying as a result of accessing the provisions of the bill and who does not request the administration of life-saving treatment. The necessity of these provisions follows logically, of course, from the purpose of the bill. If euthanasia and assisted suicide are made legal, it would defeat the purpose of such a law and be unfair if those who assisted people in accessing assisted dying were then subject to criminal or civil penalty or a professional misconduct process. The point, however, is not about what is logically required if euthanasia is legalised but where this logic takes us.

Protecting people—all people, including the weak and the vulnerable—from having their lives taken from them or ended prematurely is the cornerstone of our laws. Caring for people when they are chronically ill or dying with no intention of causing their death and trying to save people when they have been hurt are, of course, fundamental principles of our healthcare system. These fundamentals are not going to be abolished by the legalisation of euthanasia. But the fact that euthanasia can only be made legal by creating an exception to the otherwise unconditional prohibition on the deliberate taking of life and an exception to the fundamental purpose of health care based on doing no harm demonstrates how we enter radically new territory with assisted dying.

Proposing that we focus on making high-quality palliative care available to everyone who needs it—people with chronic illness as well as people nearing the end of their lives, children and adolescents as well as adults and the very old, people in the major centres and people in the remote parts of the State—is not to claim that palliative care is the solution to all suffering. Rather, it is to suggest that before we start experimenting with exceptions to the laws of prohibition on deliberately ending someone's life and health care's imperative to help and never harm, we should see what difference universal access to high-quality palliative care can make for those who are suffering and dying. As a matter of prudence, precaution and good public policy, consideration of euthanasia should only arise, if at all, once the possibilities of palliative care have been made universally available and the evidence of its impact on end-of-life care and the experience of patients at the end of life has been analysed.

A further reason for pursuing this course rather than the legalisation of euthanasia arises from the emphasis placed on choice and autonomy both in the principles of the bill in clause 4 and, of course, in public argumentation in support of assisted dying. Some amendments to the bill helped to raise the importance of access to palliative care. As our analysis shows, however, much needs to be done to ensure the same level of access to palliative care for people in outer, regional and remote areas as for people in the major cities. As noted in our submission, the bill places some emphasis on ensuring that people in regional areas can access voluntary assisted dying. For example, clause 174 (2) also requires the health secretary to include in the access standard specific information on how the Ministry of Health intends to facilitate access to voluntary assisted dying for regional residents. However, if people in regional areas do, in fact, obtain the same level of access to assisted dying as people in the cities, without also having the same level of access to palliative care, can this really be described as something that respects choice and autonomy?

Unequal access—in some cases no access—to palliative care compared with equal access to assisted dying is not a real choice. How does offering this sort of choice respect the dignity and autonomy of gravely ill people at the end of their lives? As I say in the submission, it is a false choice, one that is unjust to offer, particularly to people who are suffering terribly. The legalisation of euthanasia and assisted suicide is dangerous and wrong because it authorises the deliberate ending of a person's life either by themselves or with the assistance of others. It represents a tectonic shift for our society, our institutions and our shared values. Laws, of course, are a matter for Parliament and legislators to decide, but this step should not be contemplated before everything that can be done to enhance the care of people with terrible illnesses or at the end of their life everywhere in our State has been done. We continue to be a long way from achieving this. Thank you.

The CHAIR: Thank you very much, Dr Casey. Before I go to Dr Fleming, I did not want to interrupt you, Dr Casey, while you were making your opening statement, but we had some discussion this morning about terminology and it was made clear that this bill is not euthanasia or suicide, it is voluntary assisted dying. Some people may or may not understand the differences, but that is the terminology we have adopted.

The Hon. GREG DONNELLY: You are providing a view. I have a different view that I want to put forward.

The CHAIR: Deputy Chair.

The Hon. GREG DONNELLY: The individuals—I cannot speak for the third one yet—who have made submissions to this inquiry, along with a number of organisations and individuals—many, many have—and replete throughout many, many of those submissions is the use of the words "euthanasia" and "assisted suicide".

The Hon. TREVOR KHAN: And, in fact, we heard evidence of "assisted killing" on Friday.

The Hon. GREG DONNELLY: Yes, and "physician-assisted suicide".

The Hon. TREVOR KHAN: I just do not think it necessarily helps their case, but I think they can use any term they like.

The Hon. GREG DONNELLY: That is my very point. The idea that witnesses to this inquiry who have presented today are being told they can and cannot use certain words and phrases, I have to say to you, I find very, very distressing—very, very distressing. The language is clear in their submissions—

The Hon. TREVOR KHAN: The Hon. Greg Donnelly can take a point of order, but now is not the time for speech making.

The Hon. GREG DONNELLY: I am happy to take as long as you like here. The idea that witnesses appearing before this Committee—

The Hon. TREVOR KHAN: Point of order: Now is the time to question these witnesses. The Hon. Greg Donnelly making a speech does not advance the cause of anyone.

The Hon. GREG DONNELLY: As long as the witnesses are not going to be treated as if they have to proscribe certain words and terms.

The Hon. TREVOR KHAN: I have joined in with you and I agree with you: they can use whatever term they like.

The Hon. GREG DONNELLY: As long as that is clear.

The CHAIR: On that note, I will now pass to Dr Fleming for an opening statement.

Dr FLEMING: The case I brought to your attention in my written submission may be simply expressed in the following propositions. Firstly, that division 2 of this bill, which enunciates the ethical principles on which this bill relies, is seriously in error. The bill asserts that every human life has equal value but makes no reference to the inalienable right to life. Nowhere does the bill tell us what this equal value is. That can only be stated based upon what the Universal Declaration of Human Rights, which Australia have agreed to, describes as the first human right, namely, the right to life. The bill asserts that a person's autonomy, including autonomy in relation to end-of-life choices, should be respected. Why should this be so? The bill does not tell us the answer to that question. Why should anyone respect a person's autonomous decision? You can decide to drive a car under the influence of drugs, including alcohol, or to defame another person or to defraud the Government. The elevation of autonomy over all other considerations is a novelty in our culture and legal system, runs counter to laws in relation to our system of criminal justice, and defies common sense.

The first human right which governments are duty bound to protect is the right to live. Without that right, we have no rights. That entire division 2 runs clearly counter to the fundamental duties of the Parliament to the citizens of the State. According to the Constitution of the State of New South Wales, the first paragraph of section 5, "The Legislature shall, subject to the provisions of the Commonwealth of Australia Constitution Act, have power to make laws for the peace, welfare, and good government of New South Wales in all cases whatsoever." The first duty of parliamentarians, as anybody knows, is to secure the citizenry from threats to their peace and security, threats which may come from outside the country, threats which may come from within.

The United Nations Bill of Rights makes it clear that the right to life—the sine qua non of all other rights—is an inalienable right. This means that we cannot alienate the right to life. An innocent person's life may not be taken away, and nor may citizens give away their right to life. A parallel case is that of the human rights for freedom of autonomy: no-one may sell themselves into slavery even if they want to. The State cannot in any way legalise the slave trade. Article 4: "No one shall be held in slavery or servitude, slavery and the slave trade shall be prohibited in all their forms." In the same way, until now we have prohibited the homicide of innocent persons, even when they want to kill themselves or be helped by others to do so. Assistance in dying is a euphemism. The reality of it is that it is suicide and it is self-killing.

Making legal exceptions to the law against killing fellow innocent citizens compromises the capacity of the State to protect the lives of all its citizens impartially. People, politicians included, may legitimately disagree on whether euthanasia or a physician-assisted suicide is morally right or morally wrong. It does not follow from that disagreement that this bill should be passed. Parliamentarians need to set aside their personal moral opinions and look at the evidence before making public policy. The issue at stake is the inalienability of the right to life and the duty of the State to protect impartially the rights of all its citizens, and especially the weak and the vulnerable.

There is a superabundance of evidence to show that voluntary euthanasia and physician-assisted suicide are accompanied by as many or a very large minority of cases involving the killing of patients without their knowledge or consent. I ask you not to be swayed by emotional appeals for hard cases, which can be ameliorated by good palliative care. I ask you not to ignore the overwhelming evidence of people being killed without their knowledge or consent whenever there is a practice of euthanasia. The existence of such abuses should persuade you that you cannot safeguard the rights of citizens once the obligation of government to protect the personal security of the citizenry is in any way attenuated. There have always been doctors who think that the law does not apply to them. I refer you to pages 6 to 13 of my submission.

The State cannot supervise acts carried out by doctors since, firstly, they are done privately. Secondly, doctors will not always fill out the forms accurately or even at all. Thirdly, there has been a serious and long history of many doctors and nurses protecting each other from accountability when things go wrong. Moreover, if some doctors are prepared to break the law on homicide now, and oftentimes without the knowledge and consent of their patients, why would anyone imagine that those same doctors will be any more law abiding once a bill like this is passed. It is beyond delusional to imagine that this bill will in detail be followed by healthcare practitioners. What the bill will achieve is the [inaudible] of the medical profession.

If you must persist with wanting to provide a place for people to go who want to be killed or assisted to kill themselves, then it should not be doctors who do the killing in violation of the Hippocratic tradition. Instead, appoint a special class of persons, such as the executioners where capital punishment is concerned. This special class of persons cannot call themselves doctors or healthcare practitioners. Call them what they are and let the deed be done in facilities which are not hospitals, aged-care facilities and the like. Approving killings as a medical act by bona fide healthcare practitioners is [inaudible] support the acceptability of medical killings which we saw in Germany in the Weimar Republic well before the coming of the Nazi regime. We may each of us differ as to whether euthanasia or physician-assisted suicide is morally acceptable, but this bill needs to be faced fairly and squarely as a public policy issue, not an issue driven by stories of hard cases and personal ideologies. I conclude using the words of the New York Task Force on Life and the Law:

> Some Task Force members do not believe that assisted suicide is inherently unethical or incompatible with medical practice. On the contrary, they believe that providing a quick, less prolonged death for some patients can respect the autonomy of patients and demonstrate care and commitment on the part of physicians or other health care professionals. Nonetheless, these members have concluded that legalizing assisted suicide would be unwise and dangerous public policy.

Voluntary assisted dying is simply a euphemism for what we would ordinarily call assisted suicide and even euthanasia.

The Hon. GREG DONNELLY: Thank you all for joining us today. We appreciate it very much. Thank you for your submissions. This is an opportunity for you to provide some supplementary information through your oral evidence today. In terms of the research—perhaps first if we start with that from both of our representatives from the PM Glynn Institute. Can we perhaps start from this preliminary point of asking what is the general quality of the information that currently is able to be looked at and studied about the provision of palliative care, specifically in New South Wales. In other words, you have done some work, you have referred to some previous research, but the starting point is what is that information out there and what are your views about that information to enable one to move towards some reflections and conclusions, which you have done in your report?

Dr ABBU: You are asking about the quality of the data?

The Hon. GREG DONNELLY: Yes, what is out there to help us understand?

Dr ABBU: These are data from the Department of Health and the Australian Institute of Health and Welfare [AIHW]. So we just collated and assessed their raw data. There are problems in terms of consistent reporting, but it does not negate the insights from—that what those data or information are giving us is correct and significant.

The Hon. GREG DONNELLY: Yes. No, I was going to come to matters of reflections and conclusions in due course, but we have had evidence from other witnesses, even earlier today, I have to say, that have reflected that the detailed information that is readily available to make judgements and assessments about the provision of palliative care is somewhat sketchy and very general in its nature. The reason I am asking the question is because if this legislation is to proceed, and I have noted specifically, as I am sure you are aware, and Dr Casey has referred to this in his opening—actually it is in the cover letter to the submission—with respect to the references of some of the principles in clause 4 of the proposed legislation, specifically clause 4 (1) (d). These are underlying principles for the legislation about the provision of high-quality care, including palliative care, then jumping down to (h), which is also referred to, the issue of genuine choice, and (i) with respect to consideration for regional residents. So all that comes together. The NSW Health information that you were able to gather and interrogate—was that satisfactory for you to draw some of the conclusions? It was?

Dr ABBU: It was, because they had published data in the reports, but that is not where we got the data from. We asked them, particularly AIHW, to access the root data. It is unpublished, but we were given clearance to access it. So we actually accessed the rawest of data and then analysed it. In the submission that we gave to you, all the data there are not published yet because, if you look at the reports on palliative care, it is just national figures. But they did not go into nitty-gritty on regional and remote New South Wales—by State. So what we did at PM Glynn was to ask for permission to access the raw data and from there draw out what belongs to New South Wales, what is the picture in regional New South Wales. So it is the first time to actually publish this information but, yes, it is very—because it comes from what they call TableBuilder, which has the raw data, and we collated it and analysed it. Yes, it has data integrity, if you have to say it.

The Hon. GREG DONNELLY: Using an analogy, one can go to the Australian Bureau of Statistics and make application to specifically drill down granular data that is otherwise not published and use that to conduct your own research. That is effectively what you have done.

Dr ABBU: Yes.

The Hon. GREG DONNELLY: I have to share the questions around. With respect to the aging population—

The CHAIR: Do not feel there is any rush.

The Hon. TREVOR KHAN: No, I have got some; I will.

The Hon. GREG DONNELLY: With respect to the aging population of our doctors and nurses in New South Wales—something that we do hear about from time to time—you have picked up some commentary on that in your report?

Dr ABBU: Yes, on average they were around 50 years old and above, and this coincided with our national finding, which we did in another report. The doctors were saying, "We're about to retire in 10 years' time, so who will take over?" So the question is of who will continue the work, considering also the small number of palliative care physicians available. So that alone is a problem. If we are saying that in regional areas there is a much wider gap between the number of palliative care physicians and nurses in contrast to cities, then all the more it becomes a problem. In the seven-year period that we were studying, only one year—I think 2015—had a palliative care physician in the remote region. The rest of the year it is zero, as well as the outer region. In the inner region there were a few but most were city based.

The Hon. GREG DONNELLY: With respect to palliative care nurses—I think it was reflected in your opening statement—was that the case as well?

Dr ABBU: That is the case as well—zero—especially the outer and remote regions, while you have a number in the cities. I think the problem, which has been said in many reports, is also enticing the uptake of physicians who specialise in palliative care. That is a big problem as well. Our position really is that if there are zero in outer and remote areas there is really no choice because choice assumes that you have an alternative. But it seems like there is no other alternative because it is blank; it is absent.

The Hon. TREVOR KHAN: Dr Casey, I take it that your doctorate was in sociology.

Dr CASEY: Correct.

The Hon. TREVOR KHAN: And your undergraduate degrees were in law and arts.

Dr CASEY: That is correct.

The Hon. TREVOR KHAN: So you are not a medical practitioner in any shape or form.

Dr CASEY: Certainly not.

The Hon. TREVOR KHAN: So your assessments on the capacities of palliative care and the like are based on, in a sense, second- or third-hand information.

Dr CASEY: They are based on, as Dr Abbu has explained, an analysis of datasets which various instrumentalities used to report on the provision of palliative care and access to it.

The Hon. TREVOR KHAN: Right. We will just talk about that. You are aware that we had nurses who came along to give evidence to us.

Dr CASEY: Yes, I am, in general.

The Hon. TREVOR KHAN: I will read to you a little bit of what Ms Fleming, who is a nurse who has worked for 10 years in palliative care, said to us in evidence:

> … there are occasions where patients' suffering cannot be relieved, whether that is emotional suffering, whether it is physical suffering through symptoms of pain, breathlessness or nausea. It is really hard. There have been a lot of cases recently where people's suffering

> has not been able to be relieved, even with really high doses of opioids. It is very distressing for the patient, for the family and for the staff.

In another part, another nurse, Ms Candish, made the observation:

> As referenced in our submission to this Committee, a recent survey of almost 4,000 members found that more than 85 per cent—

that is of the members—

> are in support of voluntary assisted dying law reform. Meanwhile, 84 per cent indicated having professional experience in providing care to terminally ill patients and over half of those had been asked by a patient for assistance to end their life.

What I essentially want to put to you, Dr Casey, is this: It seems to me that your argument is that under no circumstances should there be voluntary assisted dying but, if there is, we should wait until some indeterminate time in the future when somebody determines that there is adequate palliative care across the State. Is that a reasonable summation of your position?

Dr CASEY: I think the position, as I said in my opening statement and in the covering note to our analysis, Dr Abbu summarised for us very nicely: If a lot of the argument for assisted dying is about choice, there has to be an alternative. All we have done is look at the data to see how well Australia is served in terms of palliative care services. Looking at published data and other data collected by government instrumentalities, we have found and highlighted that actually there is quite a long way to go in making sure that everyone who needs high-quality palliative care has access to it. It just seems to me—

The Hon. TREVOR KHAN: Dr Casey, even if I accept—

The Hon. GREG DONNELLY: Point of order: We know we do not talk over a witnesses who is answering a question—

The Hon. TREVOR KHAN: If I have talked over Dr Casey, I apologise.

The CHAIR: I will allow Mr Donnelly to finish his point of order.

The Hon. GREG DONNELLY: Thanks very much. Mr Casey clearly had not finished giving his answer—

The Hon. TREVOR KHAN: Dr Casey.

The Hon. GREG DONNELLY: Dr Casey. The witness must be permitted to complete his answer.

The Hon. TREVOR KHAN: I apologise. Dr Casey, go your hardest.

The CHAIR: I uphold the point of order. Dr Casey has the call.

Dr CASEY: Thank you. Just to finish by saying that, as Dr Abbu highlighted, if there is to be a choice there has to be an alternative. Our concern with palliative care was to see to what extent it is equitably and generally available for people. We discovered, looking at the published data, that it is not as much as we would like it to be. It does seem to be that there is a threshold question about whether, given the absence of choice for people when it comes to end-of-life care and care for chronic illnesses—it seems like a big jump to go straight to assisted dying when there is still much to be done to relieve people's suffering, which could make a significant difference to people suffering chronic illness or at the end of their lives.

The CHAIR: Dr Casey, just on that point and to the question that the Hon. Trevor Khan was asking, if the provision of palliative care was 100 per cent gold standard across the State, would your organisation be in support of voluntary assisted dying?

Dr CASEY: No. As I mentioned—perhaps in my covering letter—I think there are other reasons still to have reservations about, and objections to, assisted dying. It seems that if legislators and parliaments are to move in that direction, the appropriate threshold to approach it from is one where there is more or less universal access to quality public palliative care for everyone who needs it, because then it seems that everything that we can do to help people who are suffering—within the parameters of our existing approaches to health care and law—has been done. As a matter of policy that might be an appropriate threshold to then consider something which goes in a different direction.

The CHAIR: Here is the issue I have—

The Hon. TREVOR KHAN: Just hold on. Dr Casey, does that mean that at the present time your answer for those terminally ill patients who, even with the assistance of the best palliative care, are suffering unbearable pain is "You will just have to grin and bear it"? That is the consequence of your proposition, is it not?

Dr CASEY: I am sure that like everyone in this room I do not want to see anyone suffer at all, least of all at the end of life from some terrible, intractable illness. No-one wants to prolong that sort of suffering or see it go untreated or unmediated. But I think the fact of the matter is that with assisted dying there are consequences for us as a society beyond the immediate relief that such a measure might give to a particular patient. With the greatest respect—and I am sure you understand this better than I do—legislators and lawmakers have to attend to the social consequences and the broader consequences for a community as well as to how we best look after those who are vulnerable and suffering.

The Hon. TREVOR KHAN: Do I summarise that, Dr Casey, by saying you agree with the proposition that it just means that some people will have to grin and bear it?

Dr CASEY: No, I would not put it that way.

The Hon. TREVOR KHAN: You may not, but that is the natural outcome of your proposition.

The Hon. GREG DONNELLY: Point of order: Just because you do not get the answer you want, Trevor, your proposition is that Dr Casey agrees with the proposition that people "grin and bear it". I think from the answer and the sequence of answers he has given, there is not the wildest suggestion in the tone and the way in which he has communicated to the Committee—let me finish, please.

The CHAIR: Deputy Chair, I have not said a word.

The Hon. GREG DONNELLY: You were about to cut me off.

The CHAIR: I was about to uphold your point of order. But, okay, continue please.

The Hon. GREG DONNELLY: With respect to Dr Casey—

The CHAIR: I just upheld your point of order. That was my point. Dr Casey, continue, please.

Dr CASEY: Mr Khan, with respect, you offer an interpretation of my comments. That is not an interpretation that I would adopt or accept.

The Hon. TREVOR KHAN: What do you say we should say to Abbey Egan, whose partner, Jayde, died in the following circumstances? This what Abbey Egan said:

> I want you to remember that we are talking about a 32-year-old woman at this point. We are not talking about someone who is 80, not that that is any better. But at 32 years of age, this is not something that she should have gone through. She had a permanent catheter in to help her go to the toilet. Because of the pain medication she was on and because of the tumours, it was impacting her bowels so much that she was unable to go to the toilet that way, so she would end up vomiting her own faeces on the regular. The way that her tumour was positioned in her body—when I would have to change her, parts of her tumour would fall out from her, which was horrendous for everyone involved, especially Jayde, obviously. The tumour was so large in her back that it cracked her vertebrae. In terms of her being in bed, when we would have to move her so she wouldn't get bedsores, trying to roll her over—she would scream in absolute agony because of the cracked vertebrae. You could only imagine.

Dr Casey, is that the sort of person who should not be assisted by a voluntary assisted dying law?

The Hon. GREG DONNELLY: Point of order—

The CHAIR: I will hear the point of order.

The Hon. GREG DONNELLY: I think, in all fairness to Dr Casey, he is entitled to read the full transcript with respect to that witness and what that witness had to say, along with, if he wishes to do so, two other witnesses on that panel and consider the full and totality of what was said before he answers, if he wants to take it on notice.

The CHAIR: I was about to say—

The Hon. TREVOR KHAN: To the point of order: I will respond to that. That is an absolutely accurate description. I could read more in terms of the death of Jayde but for a point of order to be taken, this is the style of person that we are dealing with here.

The Hon. GREG DONNELLY: Oh, don't thump the table, Trevor, please.

The Hon. TREVOR KHAN: This is the style of person and for Mr Donnelly to be running cover on these matters is appalling.

The Hon. GREG DONNELLY: Well, I will not respond to that taunt.

The CHAIR: Look, members have been very good today.

The Hon. GREG DONNELLY: Yes.

The CHAIR: At this late hour, we are not going to descend into arguments. While I accept the point of the Hon. Trevor Khan, I will allow Dr Casey either to answer the question, as the Hon. Trevor Khan has asked, or if he feels that he needs further information, to take it on notice—although I can confirm that the member has read the transcript verbatim.

The Hon. GREG DONNELLY: Only with respect to that paragraph.

The Hon. TREVOR KHAN: I am happy to read more, if that assists.

The Hon. GREG DONNELLY: Start at the beginning and go all the way through.

The CHAIR: Order! This is not helpful. Dr Casey?

The Hon. TREVOR KHAN: No. I will read more.

The Hon. GREG DONNELLY: I want you to start at the very beginning, if that is what you want to do.

The Hon. TREVOR KHAN: No, no.

The Hon. GREG DONNELLY: The witness is entitled to know the full evidence.

The Hon. TREVOR KHAN: Ms Egan said:

> First of all, I want to say that I am incredibly honoured to be here today. It is not every day that you are asked to come and talk about life and death—and such a good death, in hopes, after we are here talking about our loved ones having a bad death. I think it is really good that you guys can talk about the safeguards and the legislation and the hoops and the paperwork and everything that you need to do, but I do not think you guys would have been able to have the full picture of what this bill would mean to people unless you were to meet people like us, who have had our loved ones go through this. My partner Jayde was diagnosed with cervical cancer in March 2017 and ended up dying in October 2018, so she lived for 18 months. Jayde was misdiagnosed for 12 months in the lead-up to receiving that diagnosis, which means that when she was finally diagnosed it was pretty progressed. She was stage four and we were told that she had 12 months to live from then, so it was fairly downhill from there.
>
> Jayde was probably the best person I have ever known. Her family and friends love and adore her, and still do. She, from the get-go, was a real advocate in terms of wanting voluntary assisted dying. I think because she was so sick from the get-go, she knew that this was not going to end very well. In her journey of having cancer she met other people with her disease and with other types of cancers who had died horrible deaths, and she really, really did not want that to happen to her. In the last six months, her disease progressed so much and the tumours in her body became so large that it impacted her on a daily basis. She had up to five kilos worth of fluid in her legs a day, which was immensely painful, and no pain relief could relieve that towards the end of her time. She wanted to die at home, and fortunately I was able to grant that wish for her and make that happen with the use of palliative care. They were unbelievable but, again, could not relieve all of Jayde's suffering.
>
> In terms of her emotional and spiritual suffering, which is just as important as physical pain, not only could her physical pain not be relieved, but her emotional and spiritual suffering could most definitely not be relieved at all. Jayde's last week on this earth was nothing short of hell, not only for Jayde but also for her family and my family, who were there to watch her leave. She was so dosed up on pain medication that she was hallucinating and thrashing around on the bed. She did not know where she was or who we were or what was happening for her, which was immensely distressing, not only for her but for us. I am going to give some gory details because I think it is really important that you hear it, otherwise it is like I said: You guys can have all the paper and all the facts, but until you hear the actual things, you do not really know. The tumour in her abdomen was so large that it was impacting her ability to use the toilet, so she had a catheter in permanently to help her go to the toilet.

I read the other paragraph. I hope that assists you in your analysis, Dr Casey.

Dr CASEY: I am happy to take the question on notice. I would just like to say that, obviously, no-one can read or listen to that evidence without being deeply moved and sorry for the terrible suffering that it describes. It is a horrible situation and a horrible picture. But I am happy to take the question on notice and all I can do, I suppose, in general, is to say what I said before: That I realise just how strongly people feel about this issue, often exactly from experiences like this, but there are other factors involved for us to consider when we look at the possible consequences of legalising assisted dying for the rest of society.

The Hon. TREVOR KHAN: Thank you, Dr Casey. I have no further questions.

The CHAIR: Dr Casey, Dr Abbu and Dr Fleming, unfortunately we have gone over our time. I thank you—

Dr FLEMING: Can I make one—

The CHAIR: Dr Fleming, we are out of time so—

The Hon. ANTHONY D'ADAM: We are out of time. We have other witnesses.

Dr FLEMING: I will be very brief.

The Hon. ANTHONY D'ADAM: He has already made an opening statement.

The CHAIR: I will permit you—

Dr FLEMING: I want to ask in relation to the lengthy speech just given to us about a particular case [inaudible].

The Hon. ANTHONY D'ADAM: Point of order: Mr Fleming does not have the right to take over. He has been given the opportunity for an opening statement. He has used that opportunity. The time has expired. We have other witnesses that we need to hear from. Time to move on. Thank you.

The CHAIR: Thank you. I uphold the point of order.

The Hon. GREG DONNELLY: And we can put questions on notice.

The CHAIR: We can put questions on notice. So thank you. The secretariat will be in contact with the witnesses to enable the tabling of questions and answers that have been taken on notice. I thank witnesses for appearing today.

(The witnesses withdrew.)

GREGORY BONDAR, NSW and ACT State Director, FamilyVoice Australia, NSW, sworn and examined

BRANKA VAN DER LINDEN, Director, HOPE: Preventing Euthanasia and Assisted Suicide Ltd, before the Committee via videoconference, sworn and examined

The CHAIR: Welcome to the next session of the hearing today and I will welcome our next two witnesses. Ms van der Linden, we did just have a slight drop out with your system just then. It will be fine for the moment. What we will do is we will monitor it and we will see how we go. We may have to go to audio only and turn off the camera. Perhaps that may assist the bandwidth but we will see how we go during the opening statements, which I am assuming you will do one. But I will first go to Mr Bondar. I assume you have got an opening statement and now is your opportunity to provide it if you would like.

Mr BONDAR: Thank you very much, Mr Chair. I do have a short opening statement. Mr Chair, members, thank you for the invitation to voice our concerns regarding the Voluntary Assisted Dying Bill second print. FamilyVoice Australia is a non-denominational national pro-life, Christian-based organisation advocating on issues of family, freedom and faith. FamilyVoice has for nearly 50 years been calling for government to respect the sanctity of life—of all human life—in particular from conception. Whilst we oppose legalised assisted suicide on religious grounds, we do believe there are strong grounds for maintaining the status quo and hence a legal ban on voluntary assisted dying.

The bill before the house is not only a bad bill but also a dangerous bill, especially to those considering suicide—disturbed youth, the lonely and the depressed in our society. The bill will result in greater death through suicide, especially the young, as it legitimises death through State-sanctioned legislation. If the Canadian experience is anything to go by, we will see similar results in New South Wales. In 2016 Canada legalised euthanasia for terminally ill adults with 1,000 medically assisted deaths, which jumped in just four years to 7,595 in 2020—the source is Canadian health. And now in 2021 under medical aid in dying, laws have been expanded to include non-terminal conditions and, as predicted, Canadian euthanasia laws will have an added mental illness provision in 2023. Is this the future for New South Wales?

In the Netherlands and Belgium, euthanasia is now legal not only for those who are terminally ill but also for those with mental illness. Whatever the euphemism advocates of the bill use, the truth of the matter is that voluntary assisted dying is actually death by assisted suicide. There is no dignity in dying. Basically death by any means other than natural cause and involuntary accidental causes is immoral and makes a mockery of the medical Hippocratic oath. Like any government legislation, there will be loopholes and this bill has so many unanswered questions that it really needs to be the subject of an in-depth government inquiry that also considers and/or clarifies the following, Mr Chair. Will due and proper consideration be given to Indigenous peoples? As a former chief executive of the Tharawal Local Aboriginal Land Council, I can attest to the fact that Indigenous people do not support assisted suicide. So much for Black Lives Matter rhetoric.

Will the bill allow assisted suicide for prisoners? If there is support for voluntary assisted dying through legal injection, then those same advocates must surely approve of capital punishment through lethal injection. Will there subsequent be amendments to end their life through telehealth? Will legislation protect patients, for example, who have not elected to partake of voluntary assisted dying; against health funds that refuse to fund continued medical hospitalisation, which is the case in the USA at the moment; and does VAD nullify death insurance cover?

Will New South Wales follow the Netherlands where the Dutch Government has approved plans to allow euthanasia for terminally ill children aged between one and 12? Will it be mandatory to be vaccinated if one wanted to go assisted suicide, given it is a medical procedure, which is now the case in Germany? I am appalled to have read that New South Wales MPs have been urged not to add further safeguards to a voluntary assisted dying bill. It was said on Monday, I believe, that there is nothing uniquely special or vulnerable about people dying in New South Wales to warrant adding additional requirements and safeguards above and beyond those already in existence—that was Dying with Dignity.

Mr Chair, the arguments in favour of voluntary assisted dying are insufficient to justify. The bill places the burden of proof onto those who value life, which is unjustified. The fact is that there does not seem to be a compelling reason or reasons why VAD should be legalised. This is a public debate. Government needs to be reminded that its primary role is to make public policy, including laws which protect the life and sanctity of its people. Australia is a signatory to the United Nations charter on the Universal Declaration of Human Rights. These rights to life and liberty are inalienable rights—the rights of a person which cannot be deprived by others or by the State and a right of which a person cannot even deprive himself or herself.

Finally, euphemisms used by advocates of VAD try to make the unpalatable seem palatable. VAD and euthanasia—and the terms are used interchangeably by many—literally mean killing according to any dictionary you pick up. Euthanasia and assisted dying are not the way to ensure a dignified and compassionate death. The choice should always be life. Whatever individual MPs consider to be morally acceptable or what opinion polls may seem to favour, it does not settle the issue. A responsible parliament must attend to enunciating public policy which meets the criteria for responsible government, chief of which is the obligation to impartially and objectively pass legislation which secures for all people their right to life and security, and especially for those who are most vulnerable. Any legislation which breaches a capacity of the State to protect its own must be voted down. Thank you, Chair.

The CHAIR: Thank you Mr Bondar. Ms van der Linden, I will now offer you the opportunity to make an opening statement if you so choose.

Ms VAN DER LINDEN: Thank you. Can you hear me okay?

The CHAIR: Yes, we have got you fine.

Ms VAN DER LINDEN: I would like to thank the Committee for allowing me this opportunity to appear before you this afternoon and I would like to particularly thank the Parliamentary staff for their very able assistance to me in all matters administrative leading up to this. HOPE has 25,000 supporters nationwide. We work with medical professionals, disability advocates, palliative care specialists, multicultural and ethnic groups, religious organisations, lawyers and academics and others opposed to euthanasia. What unites us is a desire to relieve the suffering of those approaching death by ensuring that everyone has the best end-of-life care possible no matter where they live. The current inquiry being conducted by the health portfolio committee in New South Wales has already uncovered the unequal access to health care, including palliative care, and a lack of GPs and specialists in regional, rural and remote parts of New South Wales. Deficiencies in health care mean people are currently not able to access basic end-of-life services, and treatment should be addressed as a priority.

Death is a deeply personal matter but it is not private. It has a profound impact on those close to the dying person and broader cultural [audio malfunction]. A society that accepts the view that some lives will become too burdensome eventually becomes a society that abandons those most in need and ultimately the choices available to those at the end of life. In countries where euthanasia or assisted suicide has been legalised, categories of people who are eligible to be killed have expanded while affordable care has been denied to those who would otherwise want to live, and those tasked with enforcing breaches of legislative [audio malfunction] are unwilling to do so.

These laws reduce choices for people like Stephanie Packer, a mother of four from California. In 2012,when Stephanie was 32, she was diagnosed with scleroderma, a rare condition that involves the hardening and tightening of the tissue. She was given three years to live. In 2016, a week after California's assisted suicide law came into effect, Stephanie received a phone call from her insurer that told her that her life-extending treatments would no longer be covered. Californian law prevents insurers from denying insurance coverage for treatment in the same communication as it provides information about coverage for assisted suicide. The patient has to initiate the discussion about assisted suicide coverage. When Stephanie inquired, she was told that while it would not cover her chemotherapy, her insurer would cover assisted suicide drugs for a payment of $1.20. "It almost forces the poor people, the sick people, the scared people, the people who are alone to kill themselves because what other choices are they given?" Stephanie told HOPE, "When California passed this law, they took away my choice to live."

I would like to briefly clear up some misleading information put to the Committee so far. The claim that 20 per cent of suicides in people over 40 are associated with a terminal or debilitating illness has been repeated several times. The National Coronial Information System report on which this data is taken tells us that this included reduced mobility, an inability to work, a requirement for nursing home commission, or other suffering. Many would not be eligible for assisted suicide under this bill. The report goes on to say that the data does not indicate that the condition suffered was the sole or even primary contributing factor to the deaths, nor does it infer a correlation between the condition and the self-harm. There is no justification for concluding that these deaths would not have occurred if assisted suicide was available, and the Committee should take note of the full report in its deliberations and not just extracts provided by activists.

The second misleading claim is that the expansion of laws in other countries is not relevant to the Australian situation because of several distinguishing features contained in, for example, the Canadian legal system or the wording of euthanasia laws in the Benelux countries. The conclusion we are being asked to reach is that the Australian parliamentary and legal system is so different from these that our laws would be immune from expansion. That we do not have a bill of rights in Australia does not mean that the laws will not change. Activists will just use whatever legal means are available to them in this jurisdiction to challenge existing laws. We already see it happening in Victoria, with proponents re-characterising Victoria's safeguards as barriers to access.

Finally, references to the established law in Australia grossly overstate the tried and tested nature of euthanasia and assisted suicided laws. The Victorian legislation has been operating for two years and the West Australian regime has been in place for six months. The voluntary assisted dying boards in each jurisdiction only publish minimal data based on information provided by the very people that they are policing. End-of-life choice occurs through heavy investment in health and palliative care services, particularly in regional and remote areas, increased education amongst doctors and patients about palliative care and advanced care directives, and good communication amongst healthcare providers so care is holistic. New South Wales has an opportunity to show true leadership on this issue and legislate to care for its terminally ill, not to abandon them.

The CHAIR: Thank you, Ms van der Linden for that opening statement.

The Hon. GREG DONNELLY: I thank you all for making yourselves available today and thank you in the first instance for your submissions. Ms van der Linden, if I could go to you first please and take you to your submission, which I presume you have got a copy of close by or within reach. It has a cover letter on page 1 and the submission is attached, dated November 2021. Can I take you to page 4 and going over to page 5 where you make comments and reflections about concerns with the bill, specifically with respect to the matter of coercion. I take what you have got there; it stands as written. We understand that. Can I invite you to elucidate any particular aspects of this part of your submission that deals with your concerns or, more to the point, HOPE's concerns about coercion with respect to a person provided the framework of voluntary assisted dying, as provided for in the bill.

Ms VAN DER LINDEN: The bill itself in its principles states that there is a need to protect persons from coercion, or who are operating under pressure or duress, but the way that the bill is drafted actually does not make it possible for this to occur. And we are very concerned that coercion will not be detected by the doctors who are assessing patients under this bill. Coercion is an extremely difficult thing to detect, and in the legal profession—of which, I am one—it is a very important skill, but it is really difficult to detect it. It can be overt; it can be subtle. We know that, for example, parties entering into a contract need to do so freely. If it can be found after the fact that there was pressure to [audio malfunction] coercion, the contract would be found to be unenforceable, similarly you would say with somebody's last will and testament, and then the parties are restored back to the situation as if they had not entered into the contract or they had not made their last will and testament.

In the case of assisted suicide, though, a failure to detect undue influence is not capable of being restored back to the position that the parties were in before the decision was made because the person will have died. Coercion can be suggested; it can be implied. All of us do not want to be a burden on someone else [audio malfunction] elderly parents, grandparents. The smallest remark made by a family member, even the thought that my daughter finds it a little bit hard to care for me, could make me feel that perhaps I should take this option.

The Hon. GREG DONNELLY: Following on from that and with your legal experience, and perhaps other learned minds around the table here who have legal backgrounds can help us here as well, in terms of understanding the way in which the law—I say the law as a statement—can protect a person, an individual, from coercion, how does the law generally do that as a statement of explanation? How does the law protect against coercion?

The Hon. ANTHONY D'ADAM: Point of order—

The CHAIR: I will hear the point of order.

The Hon. ANTHONY D'ADAM: Is Ms van der Linden here as an expert legal witness? I do not think she is. Why are we asking her for legal opinion?

The Hon. GREG DONNELLY: I am entitled to ask—

The Hon. ANTHONY D'ADAM: It is not the capacity that she is appearing before this inquiry.

The Hon. GREG DONNELLY: To the point of order—

The CHAIR: I will hear the Deputy Chair.

The Hon. GREG DONNELLY: It is my question. I can ask questions which I see fit within the remit of the inquiry, which is the inquiry into the provisions of the bill. The matter of coercion has been covered on numerous occasions over the past two days of public hearings.

The CHAIR: I am prepared to rule in your favour, Deputy Chair. Ms van der Linden, did you indicate that you had a legal background?

Ms VAN DER LINDEN: I do, yes. I am a lawyer.

The CHAIR: In that respect—

The Hon. ANTHONY D'ADAM: Perhaps Ms van der Linden could give us some details about her legal expertise.

The Hon. GREG DONNELLY: Point of order—

The CHAIR: Mr D'Adam—

The Hon. TAYLOR MARTIN: We are just wasting time now.

The CHAIR: I am ruling in favour of the Deputy Chair. The Deputy Chair can ask the question. I am prepared to accept the bona fides of Ms van der Linden. The Deputy Chair can continue.

The Hon. GREG DONNELLY: I am happy to repeat my question, if it is necessary.

Ms VAN DER LINDEN: Could you?

The Hon. GREG DONNELLY: Yes. The matter of coercion is raised in your submission on page 4 going onto page 5 as quite a significant matter that has exercised the mind of HOPE in the preparation of its submission. We are talking about what coercion may look like in the context of interfacing with this proposed bill, or the proposed legislation. You have already talked about potential overt or covert or obvious or less than obvious coercion. We understand that line. My question is how does the law, as broadly stated, deal with identifying coercion as a general proposition?

Ms VAN DER LINDEN: Can I state that I am not an expert on this area.

The Hon. GREG DONNELLY: That is okay. You can take it on notice if you want.

Ms VAN DER LINDEN: I might take that on notice rather than wasting everyone's time.

The Hon. GREG DONNELLY: That is fine.

Ms VAN DER LINDEN: Thank you very much.

The Hon. GREG DONNELLY: Can I take you to page 7 of your submission? At about point five on the page, the heading reads "Very little detail recorded by the Voluntary Assisted Dying Board". Do you see that heading?

Ms VAN DER LINDEN: Yes.

The Hon. GREG DONNELLY: I will not read it out but I thought you make a particularly salient comment there about noting what is provided for as requirements of information with respect to the proposed New South Wales legislation and the Voluntary Assisted Dying Board and the State of Oregon in the United States, which often receives comment during the course of discussions around this style of legislation. Is it your understanding that in Oregon there is a range of other "pieces of data" or "fields of data" collected as part of their data collection with respect to their particular end-of-life legislation?

Ms VAN DER LINDEN: Yes, that is correct.

The Hon. GREG DONNELLY: With respect to the collection of those particular matters, including psychological assessment—I will not read them all—have you formed a view about whether you think a collection of similar data would be relevant in the context of the debate we are having in the Legislative Council about the current provisions with respect to the board information that is collected?

Ms VAN DER LINDEN: I think it will be very prudent to have much more data collected about this regime. At the moment, as far as I understand, the bill only requires the person's relevant disease or illness, their age and whether they live in regional New South Wales. If, as a society, we are going to track this and we are going to really ensure that people are not falling through the cracks, we need to understand who is taking it up and the relationship with their physician. It would be so helpful to be able to collect statistics such as this, especially when it is combined with the fact that death certificates are falsified under this bill. The way the bill is drafted at the moment, the person is said to have died of their underlying illness or condition rather than by way of euthanasia or assisted suicide. So down the track we will have no way of knowing, apart from the data that is collected by the Voluntary Assisted Dying Board.

The Hon. SCOTT FARLOW: Thank you very much, Mr Bondar and Ms van der Linden, for being with us today. Ms van der Linden, I want to turn to something I found relatively concerning in your submission—if you have any further detail on it—which is at page 16 with respect to doctors being very rarely prosecuted for breaches. You make the claim:

> … in Quebec, 62 deaths … were deemed by the Commission on End-of-Life Care to have been a result of abuse by the doctor who prescribed and administered the lethal injection, but none was recommend for prosecution.

Do you have any further information you could share with the Committee with respect to that and the reasons that there was no action taken in those instances?

Ms VAN DER LINDEN: I could not speak to the reasons no action was taken but that is the case, and that is from the Government's own reports. The fact is there is very, very little prosecution of any decisions made, no matter what country you look at, after the fact when it comes to prosecuting doctors. In the Netherlands we saw the case of a woman who had written a living will and said that she wanted to receive euthanasia when the time was right. She had dementia. As it transpired, she went into a nursing home and there was a decision made by the doctors that perhaps it was time for her to receive euthanasia. So the doctor gathered her family round, put a sedative into her cup of coffee and when the woman resisted, the doctor asked the family to hold her down while she administered a lethal injection. This case went all the way to the Dutch Supreme Court, which ruled that this was within Dutch law. It is very, very rare to see the prosecution of a doctor in any jurisdiction. In fact, I would go so far as to say that the laws are drafted in such a way that the safeguards protect the medical professionals, not the patients themselves.

The Hon. SCOTT FARLOW: I have one further question. With respect to the Voluntary Assisted Dying Review Board, you make the criticism that there are no medical specialists who are required to be on that board, and I think you refer to the Khan bill of 2017 with respect to its requirements.

The Hon. TREVOR KHAN: I am honoured.

The Hon. SCOTT FARLOW: That was a criticism that was made from some of the medical representatives with us today as well. I wanted to see whether, from your knowledge, any of the other States have that in place in terms of their voluntary assisted dying regimes, and if not, why you think it is important to have medical professionals on that board.

Ms VAN DER LINDEN: I do not have the information at hand about the other jurisdictions, so I can take that on notice. I do think it is really important to have medical professionals on the board, particularly not ones who necessarily are ideologically supportive of euthanasia and assisted suicide, so that you can have proper oversight and checks from the medical professional, given it is a task given to medical practitioners.

The Hon. TREVOR KHAN: Ms van der Linden, are you aware that under the law in New South Wales even when a person commits suicide there is not a requirement that suicide be listed on the death certificate?

Ms VAN DER LINDEN: I was not aware of that.

The Hon. TREVOR KHAN: Indeed, if one is to appear in the Coroners Court, one of the questions that will be asked in closing submissions will sometimes be, in the case of a suicide, what submissions are to be made on what should be shown on the death certificate.

Ms VAN DER LINDEN: Yes.

The Hon. TREVOR KHAN: What I am essentially putting to you is even though you say it should appear, would you not agree that the death certificates are not a source of the collection of information for the purposes that you seek data collected?

Ms VAN DER LINDEN: Sorry, could you repeat the question?

The Hon. TREVOR KHAN: The death certificate is for the purposes essentially of use for other purposes, including for the family, not for data collection purposes.

Ms VAN DER LINDEN: But if voluntary assisted dying was a compassionate and really positive development, as proponents of this bill would say, what is the problem with having it on the death certificate? [Disorder].

The Hon. TREVOR KHAN: Let me suggest to you this, Ms van der Linden: I do not think anyone thinks that somebody who is forced into the predicament of a terrible death through one way or another, it is particularly something that anyone should be proud of. I am not quite sure, as a proponent of these laws, that I see why it is necessary for the purposes of recording a death for that material to appear on the death certificate. You tell me why. If it is not for data collection purposes, what other purpose is it for?

Ms VAN DER LINDEN: That is because it is factual. The person does not die from an underlying illness or condition, they die from a lethal injection or by taking the lethal substance.

The Hon. TREVOR KHAN: So, Ms van der Linden—

The Hon. GREG DONNELLY: Can I just—I do not want to cut into time, but just for a matter of clarity sake—

The Hon. TREVOR KHAN: No. You are taking my time.

The Hon. GREG DONNELLY: Well, I—

The Hon. TREVOR KHAN: Point of order: I was given the call.

The Hon. GREG DONNELLY: Sure, okay.

The CHAIR: Mr Khan has the call.

The Hon. TREVOR KHAN: With regards to this issue of prosecution that you were asked questions by Mr Farlow about, I take it "prosecution" refers to criminal prosecution. Is that right? He was referring to page 16 of your submission, "Doctors are very rarely prosecuted for breaches."

Ms VAN DER LINDEN: There is criminal and civil prosecution, but yes.

The Hon. TREVOR KHAN: Is it a criminal prosecution that you are referring to?

Ms VAN DER LINDEN: I am referring to [audio malfunction].

The CHAIR: Sorry, Ms van der Linden, I think your audio just dropped out again. Perhaps when you are too far away from the computer system it may not pick you up.

Ms VAN DER LINDEN: I beg your pardon.

The CHAIR: I will just ask you to repeat your previous answer, if that is okay.

Ms VAN DER LINDEN: In the submission I say, "No doctor has been successfully prosecuted for violating a safeguard in the Netherlands." My understanding, and I need to go back and check it, but that is criminal and civil in the Netherlands.

The Hon. TREVOR KHAN: Right. Could you take that on notice and get in touch, because it seems to me the use of the term "prosecution" normally refers to a criminal matter as opposed to disciplinary action, which is called precisely that: "professional disciplinary action". You would agree?

Ms VAN DER LINDEN: Yes.

The Hon. TREVOR KHAN: I think because it has got a footnote of "Ibid", I go back up and this is referring to the Oregon Public Health Division. Is that right?

Ms VAN DER LINDEN: The Netherlands?

The Hon. TREVOR KHAN: Yes.

Ms VAN DER LINDEN: And then Quebec, the paragraph with the [inaudible] in Quebec.

The Hon. TREVOR KHAN: Right, so that is 29. Fair enough.

The Hon. SCOTT FARLOW: Yes, Martin A.

The Hon. TREVOR KHAN: You referred to the question of the doctor in the Netherlands. That doctor was prosecuted, was he not?

Ms VAN DER LINDEN: She.

The Hon. TREVOR KHAN: Sorry, was she not?

Ms VAN DER LINDEN: She was. She was unsuccessfully prosecuted, but she was prosecuted.

The Hon. TREVOR KHAN: That is right, but she was prosecuted for whatever she did or did not do.

Ms VAN DER LINDEN: Yes.

The Hon. TREVOR KHAN: So there are circumstances, notwithstanding whether it is successful or not, for it. Even under the Dutch provisions prosecutions have been launched.

Ms VAN DER LINDEN: It is very rare, Mr Khan, it is extremely rare, and the only time it happens is when the family is unhappy and has to go through the courts, and it takes years. It is very, very rare though.

The Hon. TREVOR KHAN: Indeed. I have got nothing more.

The Hon. GREG DONNELLY: Thank you, Chair. I have got a couple of questions for Mr Bondar, but I will just go back to Ms van der Linden. If you need to take this on notice to clarify matters do so, but I have to say I was a little bit confused with respect to the previous line of questioning about the collection of data, which in my line of questioning was relating specifically to page 7 of your submission and data with respect to the collection by the voluntary assisted dying board and data or, dare I say, information that may or may not appear on a person's death certificate. I must say I was not quite sure whether the questions were going to questions around information on the death certificate, the information collected, which was my line of questioning, or whether or not there was some conflation there.

The Hon. TREVOR KHAN: No, mine was to the death certificate.

The Hon. GREG DONNELLY: Okay, so just that. You understand then, just so you are clear, that your answering of all those questions that just emanated from the Hon. Trevor Khan's questioning relates to death certificate information, not VAD board information? You understand that?

Ms VAN DER LINDEN: Yes.

The Hon. TREVOR KHAN: I am not cavilling, Greg, with regard to information collected by the board, not at all.

The Hon. GREG DONNELLY: No, no, no, absolutely not. Mr Bondar, thank you once again for your submission and coming along today. The matter of decision-making capacity and the significance of that, and with respect to your submission, whilst the pages are not numbered, and I am not particular about it, after the start of the substance of the submission it just turns over to the heading "Decision Making Capacity (DMC)". Have you got that? It is after those useful links that you have got, two pages in.

Mr BONDAR: Yes.

The Hon. GREG DONNELLY: With respect to the matter of decision-making capacity and the matter of consent to the decision presumably being made by the person in consideration of what is before them of going down this particular path of voluntary assisted dying, is it the evidence of Family Voice Australia that there are concerns that exist with respect to, as you understand it, what will be the operations of the bill, if it was implemented, around clarity and certainty with respect to decision-making capacity and matters of consent, particularly if the issue of coercion is added as a dimension to the whole matter, and that coercion being either overt or covert coercion. I would ask you to express a view about that if you could.

Mr BONDAR: Yes, thank you, Deputy Chair. The concern over decision-making capacity is an issue and the best example I can give you really is in the case of my own brother, who is an ex-Vietnam vet, where I went to his bedside—some years ago, mind you—where he was just drugged up and the doctor said, "What do you want to do with him?" I said, "Well, I certainly can't ask him because he's not capable of making a decision." He said, "What do you want to do?" And I said, "I want to hold his hand and pray with him until he dies peacefully".

So the point I am making here, Deputy Chair, is that decision-making can be impaired, it can be coerced, it can be indirect and it all depends on how one defines the ability for a person to be able to make a decision. The patient needs to satisfy that they have decision-making capacity. That is very difficult, Deputy Chair, very difficult, and I suspect no legislation will be able to clearly define what capacity is. I know legally there is a dictum that says "Does this person have a capacity to make a decision", as in the case of minors, for example. So it is very difficult. That is what I am referring to—that it is going to be very hard to prove that the patient has been able to make a valid and concerted and considered decision.

The Hon. GREG DONNELLY: With respect to—

The CHAIR: We have only about a minute left. If you have—

The Hon. GREG DONNELLY: No, if time is up, time is up. Whatever, keep to time. We can put it on notice.

The CHAIR: I apologise to the witnesses. We are on a very tight schedule today. We have reached the end of the session. I thank both witnesses for appearing today. For the questions that have been taken on notice, the secretariat will be in contact with you to organise the tabling. Once again, thank you for taking the time and for your submissions.

(The witnesses withdrew.)

(Short adjournment)

SHANNON WRIGHT, Chief Executive Officer, Seniors Rights Service, affirmed and examined

BEVERLY BAKER, Chair, Older Women's Network NSW, affirmed and examined

MEAGAN LAWSON, Chief Executive Officer, Council on the Ageing NSW, affirmed and examined

KAREN APPLEBY, Manager, Policy and Campaigns, Council on the Ageing NSW, affirmed and examined

The CHAIR: Welcome back to our afternoon session. We have four witnesses. There is an opportunity for witnesses to make an opening statement. Does each member of the panel have an opening statement?

Ms LAWSON: I will be doing the opening statement for Council on the Ageing NSW. Thank you very much for the opportunity to be here today. Council on the Ageing NSW, or COTA NSW, is a not-for-profit, consumer-based organisation. We have been working with older people in New South Wales since 1956. I am the CEO of COTA NSW. I am also joined by Karen Appleby, the manager of policy and campaigns. COTA NSW supports this bill and the legalisation of voluntary assisted dying in New South Wales. The question of voluntary assisted dying is fundamentally a question of autonomy and agency. Every person deserves the right to make informed choices about their end-of-life care and that includes older people. COTA's position is based upon the strong and ongoing support for VAD that has been expressed by older people in New South Wales. Our most recent findings, published in the *State of the (Older) Nation 2021* report in June this year, indicated that 72 per cent of older people in New South Wales support the introduction of voluntary assisted dying.

COTA NSW supports the provisions in the bill in its current form, including the amendments agreed to in the Legislative Assembly. The bill builds on previous work in other jurisdictions and contains robust safeguards to ensure that people seeking voluntary assisted dying are protected from coercion or malpractice. The current bill balances the rights and choices of the terminally ill person with the necessary protections for healthcare workers and those institutions seeking exemptions. Opponents to the bill have raised concerns regarding the possible coercion of older people and assessment of adequate decision-making capacity. The bill contains multiple safeguards to ensure that no-one is coerced or pressured into a premature death. This includes independent medical professionals and strict eligibility criteria and penalties, including criminal offences. Additionally, the Victorian Voluntary Assisted Dying Board has found no evidence of coercion in that State with the individuals who have died under the Victorian legislation. If anything, family members are actively discouraging their loved ones to undertake VAD.

The question of assessing decision-making capacity has also been raised as a concern. The bill defines several measures on which to determine decision-making capacity before an application to access VAD may proceed, including escalation of the practitioner to other health practitioners with different skill sets and qualifications if there is any uncertainty. In a discussion around decision-making capacity, it is important to be alert to the assumption that older people are, by definition, vulnerable and may be impacted by reduced cognition. This is just ageism. All applications to utilise VAD and subsequent eligibility should be determined by each individual's unique circumstances, including their level of cognition and decision-making capacity, and not be influenced by age-related biases and conjecture. It is COTA's belief that older people in the last stages of a terminal or incurable illness have the right to make informed decisions on their end-of-life medical care, including the choice to receive medical assistance to end their life peacefully and at a time of their choosing.

The CHAIR: Thank you very much for that. Ms Baker, could I invite you to make an opening statement?

Ms BAKER: Yes, you certainly can, but I will have to wing it, I am afraid. My written opening statement is sitting on the bench at home where I rushed out the door without it.

The CHAIR: Sometimes the ones that are winged, as you say, are the best, so I look forward to it.

Ms BAKER: As I said before, I am the chair of the Older Women's Network NSW and president of the national association. Both organisations, even though it is not a national matter, apart from in the broadest sense, support the legislation and the amendments that were accepted and passed through the lower House. I do not do that off the top of my head or off the cuff; we have recently had two annual general meetings where the agreement to support the voluntary assisted dying bill with the checks and the balances that are absolutely clearly in there was passed unanimously. We do not believe that anyone should be subjected to someone else's interpretation of a religious law regarding what happens in terms of their health at their end of life when they are in a situation where there is no other way out but pain and isolation.

Older women are not afraid of somebody stealing what little money—or a lot of money—they have; they are more afraid of being locked into an absolute routine of prodding and poking and loss of humanity and dignity and insult as they live out what will probably be some of the worst days of their lives. We would much prefer to be able to negotiate with our loved ones and our medical practitioners to determine for ourselves the time and the manner of our passing when we know that we are at those last stages so that we have the opportunity of saying farewell to our loved ones; when we still have capacity to do so; and when we can actually negotiate, debate and argue about the terms of the will so that there is no misunderstanding about who gets what. We would then be able to pass in loving arms, surrounded by people who we know love and care for us and are sad to see us go. We prefer that than to have to suffer in absolutely unmentionable and abject pain.

I know that because my mother died in such a way. She had Merkel cell skin cancer. I was powerless to help her because I would have gone to jail had I. Yet she begged me to do something as she lost her capacity to swallow. Her pain—I do not know whether anyone knows about Merkel cell skin cancer, but it is the most hideous form of skin cancer. It manifests itself in the blood and it ends up anywhere. When she first had a diagnosis we were told she had six weeks, six months or six years—nobody knew what. But they did know she was going to die in agony, and die in agony she did. It was devastating for the family and it was devastating for her, as a strong woman who had always lived her life independently, to be subjected to being completely and utterly dependent and at the mercy of a nursing home that she did not like or trust and not being able to go when she wanted to. Thank you.

The CHAIR: Thank you, Ms Baker. That was a 10 out of 10 if that was off the cuff. Ms Wright, I invite you to make an opening statement.

Ms WRIGHT: Thank you, and thank you for the opportunity to present at today's hearings. I am Shannon Wright, as I said before, and I am the chief executive officer of Seniors Rights Service. We are a community-based organisation that has been representing, supporting and advocating for the rights of older people across New South Wales for the past 35 years. Our vision is for a society that respects and upholds the rights of older people. We have a free legal service and also an aged-care advocacy and education service. Last year we responded to around 9,500 inquiries, including close to 3,000 to our legal service and over 5,000 to our aged-care advocacy service. One-third of all those inquiries came from older people living in regional and remote areas of New South Wales.

We have a network of regionally based New South Wales advocates, and we are one of a group of nine similar organisations across the country that are members of the Older Persons Advocacy Network. Unfortunately, the people who seek out our services too often bear witness to appalling breaches of the most basic of human rights: the right to be safe and live free from harm, the right to be treated with respect, the right to make independent decisions about care and treatment and end-of-life arrangements, and the right to be listened to and have their culture and beliefs recognised. Today I am speaking on behalf of the Seniors Rights Service, and we support the Voluntary Assisted Dying Bill. We acknowledge that dying is a normal part of life and that all people in Australia should have, regardless of where they are living, access to high-quality specialist care, including holistic palliative care, and the same choices available to them at the end of their lives.

People have the right to make decisions about medical care and end of life, including voluntary assisted dying. We recognise that VAD enables eligible adults who are in the end stages of terminal illness and suffering intolerably to end their suffering at a time and place of their choosing and with their loved ones if they wish. We believe that it is imperative that older people's wishes and beliefs be respected. Voluntary assisted dying must indeed be voluntary and sought by the person themselves, not by carers, families or other individuals. Medications can be self-administered or they can be administered by a suitably trained medical practitioner. Only those people who are already dying from an incurable, advanced and progressive disease, illness or medical condition should be able to access voluntary assisted dying. However, we caution that advanced age, mental illness or disability alone should not make a person eligible to access voluntary assisted dying.

We note that the criteria for demonstrating eligibility to access VAD may differ across jurisdictions, and generally includes life expectancy, residency and demonstrating that a decision to access VAD is made voluntarily. The importance of ensuring that any decision made on voluntary assisted dying is based on a person's wishes cannot be overstated. Our legal service encourages people to have in place an advanced health directive that could indicate a person's wishes regarding treatment options under certain circumstances. The existence of an advanced health directive indicates the person has thought about the quality-of-life issues as they age and may be affected by certain medical conditions. More education and information on these instruments needs to be available throughout the community, with special care taken in how this information is provided to culturally and linguistically diverse communities.

With regards to palliative care, we agree that every person living with a life-limiting illness should always have equitable access to quality, needs-based palliative care at any point in their illness journey, with timely referrals to specialist palliative care if required. Palliative care has a key place in supporting people at the end of life and we note the significant high-quality supportive care that many palliative care nurses provide to people and their families at the end stages of life. However, we also acknowledge that for some individuals palliative care is not sufficient to ensure a dignified death. Our society must ensure that the human rights of older people are respected and acknowledged and that those rights may include the right to a good quality of life, not a life of pain and suffering. Indeed, even the best palliative care services cannot always alleviate all the suffering experienced by a person. Some older people may not want to access palliative care, and this wish must be respected.

We must also be careful not to assume that everyone is living in cities with ready access to quality palliative care and other medical facilities. Indeed, many people in outer regional, rural and remote areas of Australia simply do not have access to those services. Senior Rights Services recently spent some time in Far West New South Wales talking with older people in towns from Broken Hill to Bourke about their experience of aged care and other services. What we repeatedly heard was that there was a lack of access to various medical services and to doctors and other allied health professionals. So palliative care options might be very limited for people in rural and remote areas. Therefore, any requirement to first access palliative care before being able to access voluntary assisted dying may be problematic if the services do not exist where the person is residing. In addition, the requirement for three medical practitioners to be involved in any decision about voluntary assisted dying could prove problematic in regional and remote areas where often there is only one medical practitioner in a town.

The proposal to expand the number of medical practitioners to be involved in any decision about voluntary assisted dying for a particular person could prove extremely problematic in regional areas where there are just not that number of medical practitioners available. It is our experience that while many of the people we assist reside in aged-care facilities, we do provide services to many people who are still living at home. We know that many of those people want to die at home and would not be willing or able to travel to larger cities in order to access the proposed medical assessments by a psychiatrist, for example. We believe that the proposed legislation does set out the preconditions to provide dying with dignity and that the checks and balances outlined are sufficient to ensure the person understands the decision they are making and can exercise choice. However, specific information about voluntary assisted dying must be provided by medical practitioners and allied health professionals.

We also note in the legislation there is a reference to family and to consulting with family. The notion of who constitutes a family needs to be broad enough to include those people designated as family by the individuals. As noted in the LGBTIQ health alliance submission, protection from unwanted involvement by biological relatives is important, given the lack of support and acceptance that many LGBTI people experience from their biological relatives. The widespread and ongoing use of exclusionary definitions of family that presume the default authority of biological relatives and the default lesser status of non-biological relations whom people have designated as their family is a major problem in Australia.

Again we found when we consulted with older people in remote regional locations that their biological families had often moved away and lost contact with them. Therefore, it may not be possible to have biological families present at the time of making a decision to request VAD and other people of significance the individual may need to be involved and included. We believe dying with dignity, the right not to suffer immeasurable pain or anguish and the right to self-determine and agency are fundamental human rights of all people and that these rights must be respected. Thank you for the opportunity to be a witness here today.

The CHAIR: Thank you, Ms Wright, for that opening statement. I am just noting the time. We have a little bit less than half an hour to ask questions.

The Hon. TREVOR KHAN: Ms Baker, I will start with you because you spoke in terms of your experience with your mother. I am not going to ask you to go through that in detail. We have received a lot of evidence with regard to what I will describe as bad deaths, but some of the evidence that we received, particularly on Friday, was from a number of specialists, actually, who said, "Look, all you're doing is hearing from the family"—self-evidently the deceased was gone—and it seemed to me that the suggestion was that the family had a different view as to the wishes of the deceased than actually the deceased may have expressed. So are you certain that your mother had a view as to what she wanted to do towards the end of her life?

Ms BAKER: As clearly as she could say, is, "Make this stop. Get me something so I go to sleep and I never wake up." I think that is about as clear as it could get. We were fortunate. My mum was a very religious woman. I am not; she was. When she was at the end we called in the priest who offered her absolution and she died in my arms, but she died in agony. We had to give her morphine to try to relieve the pain. I would not wish that on someone I absolutely loathed, let alone someone that I adored, and my mum is somebody who has been dead for 20 years now. I miss her every single day. I would never swap that. I currently have two girlfriends: one suffering from pancreatic cancer and the other from cancer of the liver. We all know that those things are not curable.

We know that they are heading towards the end and both of them have said, "If you can get this through, get it through because whilst we will try everything now when we are fit and able to do so, when we are told, 'The time is up and we can't do anything more', we want the opportunity to be able to die with dignity." "With dignity" were not their words but, "We want to be able to choose our own time when we go and how we go and be surrounded by those who we invite to be with us." I think that is basically it. One of those women is 10 years younger than me and the other is 10 years older than me, so that is a pretty broad cross-section of a generation that actually believe that they do not want to go through the pain and the agony that they have witnessed their parents, their loved ones, go through. They do not want to subject their family to that. I certainly never want to put my children in the position that I was in as I watched my mother go through that dreadful experience.

The Hon. TREVOR KHAN: Thank you. Seeing it has been used today, back into 2017 when I was promoting what has been described as the "Khan bill", somewhat unfortunately, one of the experiences that I had in moving around a variety of meetings—and this is my estimate—was that in the order of two to one, the audience of groups that I addressed were women. Now, if I am right in that assessment, that the interest in VAD seemed to be proportionately stronger among women, have you got a theory as to why that might be? I did not, but I am not giving evidence.

Ms BAKER: Again, only from a girlfriend who 15 years ago died from cancer of the liver. She asked if I would look after her husband because he would never cope with what she was going through. I think that there is that strong will for women to protect those who they love and who love them and I think that is very, very strong. I have not had any men die in a painful way. My father was 99 and died in his sleep—not very painful, I do not think—but I have not had any close male friends who have gone through this. It has been close women friends and they think long and hard and very, very deeply about what they are going through and the impact that will have on their family. That is why I am not surprised that it went through both the national conference and the State conference unanimously to support voluntary assisted dying.

The Hon. TREVOR KHAN: Ms Wright, Ms Lawson and Ms Appleby, do you have any views on the matter?

Ms WRIGHT: As I think about this, I think that women access health care much more often than men do. Women are more vocal than men are. Women fought to have women's health services. Women tend to have more to say on these issues than men who kind of let that happen. I just think—I do not know what sort of meetings you had, but maybe the representation is around—

The Hon. TREVOR KHAN: Most of them were good.

Ms WRIGHT: —maybe the representation was about women coming out and being vocal about that. I think about my dad. My dad would never have gone to anything that spoke about this, but my mum quite passionately would. So they are my thoughts.

Ms LAWSON: I would agree. I think, though, that when we speak to men who volunteer with us or men who are engaged with us, it still breaks in the same kind of numbers in terms of who supports it and who does not support it. I just think that there are more women who are more engaged in community groups and who do that kind of thing as part of their general being, really. But when I think of a meeting I had last week with a group of volunteers and they were all supportive, and that was across both genders and it seems to be across that way. When we get people to write again—when people write in saying that they do not agree with voluntary assisted dying, again it is a pretty equal number of men and women. It is just that I think you tend to have more women engage with these kind of debates.

The Hon. TREVOR KHAN: My perception of the evidence is somewhat like this. The nurses association comes along and says, essentially, that its members strongly support assisted dying. I do not want to verbal anyone but that seemed to be where I got to on that evidence. Various palliative care specialists have come along and said, "No, don't need it now, small issue, too many dangers involved." Have you got a view as to why the nurses seem to have a very clear and articulated view and yet among the specialist cohort, there seems to be greater caution in terms of legislation such as this? Ms Wright?

Ms WRIGHT: Look, I would think that the nurses are at the coalface. I would think that the nurses are dealing with this day in and day out. Yeah, that would be my thoughts.

Ms LAWSON: I agree and as much as we have strongly lobbied for accessible palliative care everywhere, it is not, and nurses see people day in and day out. That has certainly been the discussions that we have had with the nurses federation as well.

Ms WRIGHT: I know that when my dad passed away at home, the nurse came out. Like, he was in hospital and he came home. He was very unwell. He was not awake and the nurse came around the day before. She was an outreach nurse. She came and gave him his morphine and gave him his everything and then the next day he was breathing very badly and she came out and said, "Okay, so say your goodbyes and it will probably be about 20 minutes", and administered that last dose. So, I mean, she is on the coalface of this.

Ms APPLEBY: I think nurses are actually forming relationships with people at that stage of their life much more than a specialist would. So they get to know the experiences that they are going through, what their state of mind is and their attitude to passing on. So I think it is just a much more personal relationship and they have got a much bigger handle on things.

The Hon. TREVOR KHAN: I would like to ask you more questions but I cannot monopolise the conversation, so I will hand over to others.

The CHAIR: I am going to pass now to the Deputy Chair and the Deputy Chair has asked that we provide you with some documents.

The Hon. GREG DONNELLY: Thank you. I am just passing around to you submission No. 57 to this inquiry. This is a submission from the Australian and New Zealand Society for Geriatric Medicine—New South Wales Division. Perhaps in some sense through the answering of questions, in fact, the last one or the penultimate one from the Hon. Trevor Khan, you may have formed a view about this anyway, but I would like to press on and raise it with you, if you do not mind. I will ask just a couple of questions because we need to share around. The organisation is the specialty college for geriatric medicine in Australia, the specialists. As you will see from the second paragraph, they have 1,300 members around Australia, so it is quite a relatively large college. These are individuals, men and women, who have done the specialty training to pass through the college and ultimately to be recognised by the college as geriatric specialists. I just want to raise some of their comments because they are approaching this from their point of view as specialist doctors whose whole life is treating older people, geriatric people. If we go down to the bottom of page number one, you will see in that paragraph above the number one, which is the first point, the college says:

> Having reviewed the 2021 NSW VAD Bill, we recommend that the Honourable Members of the NSW Legislative Assembly and the NSW Legislative Council consider the following in their deliberations …

So they are asking us to think about these things in our deliberations. We obviously know it has passed through the Assembly with some amendments, but this is directed to members in the Council, who are represented around the table today. I will just skip through some of their concerns. In the first one, the college says:

> We are concerned that frail older people—

so it is talking about frail older people—

> may be put in a position of considering VAD because they feel that they are 'a burden' on others (such as family members, carers and the health care system). Such feelings are often due to underlying depression, lack of availability of community services or family dynamics. It is possible that someone may consider an older frail older person eligible on the grounds that they have a limited life expectancy.

That is a statement from the college of geriatric doctors in Australia. Do you have any comment about that paragraph that I have just read about the concern for the frail elderly? I am not talking about the ones that are obviously in pretty good shape and all of that, so to speak. We are talking about the frail older person and these specialist doctors' specific reflections of their concerns with respect to those individuals. Do you have a comment about that paragraph? We will start with COTA in the first instance, if you like.

Ms LAWSON: I am happy to say that I think there is already a kind of process and a framework in place for assessing capacity and the capacity for people to make these kinds of decisions, and those kinds of things are made routinely in health care as people are going through treatment. So if someone is going through cancer treatment, for example, there will be an explanation of what the process is and whether or not the person wants to go through that next step. So I think the medical practitioners, like legal practitioners—we run a legal service, for example, for people to make wills and powers of attorney and enduring guardianship, and those legal practitioners are required to make an assessment on the capacity of the person to make those decisions. So I think there is a routine and a process in place that covers that already. I have obviously not read this entire document because I have just had it handed to me here.

The Hon. GREG DONNELLY: Sure.

Ms LAWSON: If you look at the second paragraph where it says, "We have a predominant role in the management of dementia in each of these settings", people with dementia would not be eligible to access VAD under the bill that is before the Parliament at the moment. And so I do not think that is something that—I would suggest that if you are dealing with those people who are at that frail end of life, you are probably coloured by dealing with older people who are at the frail end of life. I think that we have to rely that there are routines and processes and procedures in place across medical and legal fraternities which cover this every single day now, and it is just an extension of that to do it under the legislation that you are considering.

The Hon. GREG DONNELLY: So your evidence, if I understand you, Ms Lawson, is that it is an extension of what is being done now?

Ms LAWSON: I believe so.

The Hon. GREG DONNELLY: That is your position of COTA, that it is an extension of provisions now?

Ms LAWSON: Yes.

The Hon. GREG DONNELLY: Okay. I will just continue on. At the bottom of that page—so this is the position of the geriatricians—it says:

> An older person requesting VAD should have access to comprehensive clinical assessment to address medical, psychological and social aspects of health to ensure management options for conditions amenable to treatment have been discussed. We do not believe the proposed Bill has adequately addressed this issue.

Ms LAWSON: I am not a geriatrician and I cannot tell you what they think. They have obviously stated what they think. But we have looked at this bill and we believe that there are 17 steps in place and that is adequate for people to be assessed as being competent and able to make that decision for themselves.

The Hon. GREG DONNELLY: Okay, let's go on to point number two. So these are the specialist doctors who look after our geriatric citizens in New South Wales. Point number two:

> The risk of potential coercion of vulnerable patients, by family members, carers or health providers is a significant concern.

Ms BAKER: To whom? Sorry, I was going to say, to whom? Certainly not to—

The Hon. GREG DONNELLY: I have not finished.

The CHAIR: You did pause, so it was not that she was interrupting.

The Hon. GREG DONNELLY: No. It says:

> Coercion (a form of elder abuse) can be subtle and difficult to detect. Patients are often subject to subtle coercion, for example to accept admission to residential care or to control their finances.

These are geriatricians making this statement, so you would have to at least give some weight to them making their submission based on what they have observed and seen. That is what one does with respect to making submissions to the inquiries, like you obviously have done. That is a pretty strong statement by geriatricians:

> The risk of potential coercion of vulnerable patients, by family members, carers or health providers is a significant concern.

What do you say to that?

Ms APPLEBY: Can I just say, to be eligible there is pretty strict criteria in the first place. You have to have a life-limiting illness and you have to be diagnosed as only having six months to live.

The Hon. GREG DONNELLY: Or 12.

Ms APPLEBY: Yes. At every stage there are opportunities for the coordinating practitioner to escalate to external experts if the person does not have capacity or they are not in a position to adequately assess whether they can go forward. That would include picking up issues of coercion. I would also say that there has been no evidence of coercion in the Victorian situation. There is a report from the board there that actually says they were looking out for it very carefully and there was absolutely no evidence. So I think there is the fear there but there is no evidence that it is actually occurring.

The Hon. GREG DONNELLY: On this point, that paragraph I have just read, the second sentence says, referring to patients of these geriatricians:

> Patients are often subject to subtle coercion, for example to accept admission to residential care or to control of their finances.

So that is what these medical specialists are saying goes on. That is what they are saying goes on. Putting aside for a moment if you could what you have just said about the Victorian report, are you saying that what they are saying is not your experience or not right?

Ms APPLEBY: I think there is a big difference between possible coercion about going into a residential aged care to coercion about ending your life earlier than is natural. That is a really big leap.

Ms LAWSON: I would add to that that there are mechanisms in place to ensure that you get the actual position of the person rather than the family. No lawyer would make a will for someone where there was a question of capacity without having a meeting on their own with that person rather than having family present, and I would assume that those are the kinds of things that are in place at the moment to make sure that you are getting the view of the person, not the view of the family.

The Hon. GREG DONNELLY: May I just take you to point number 3? Because my time is going to run out and there is plenty more to come and I am finding your responses interesting.

The Hon. TREVOR KHAN: That is actually—

The Hon. GREG DONNELLY: No, because I want to come back around—

The CHAIR: Order! Mr Khan are you taking a point of order?

The Hon. TREVOR KHAN: No.

The CHAIR: Mr Donnelly, you have the call.

The Hon. GREG DONNELLY: On point number 3, can I just go down three paragraphs, where it states:

> Patients may also be prescribed medications capable of impairing capacity.

These are obviously reflections from geriatricians who have been around the block and seen the way in which our elderly, particularly the old infirm ones in particular, are treated by people, even as close as family members. It says there in the next sentence:

> There is no requirement in the Bill for the Coordinating or Consulting practitioners to have expertise in capacity assessment.

In other words, the bill provides for capacity assessment but there is no requirement in the bill that the individual undertaking the capacity assessment in fact has that expertise to undertake capacity assessment.

Ms LAWSON: My understanding was that there was and that people would be trained in capacity assessment.

The Hon. GREG DONNELLY: The geriatricians are saying there is no requirements—

Ms LAWSON: But I think they are wrong. I think there is the requirement in the bill as it stands at the moment for people to be trained in capacity assessment.

The Hon. GREG DONNELLY: Can I invite you to take that question on notice?

Ms LAWSON: Certainly, but I think you should also go back to them and ask them to review their understanding of the bill.

The Hon. GREG DONNELLY: No, I am inviting you to take it on notice.

The CHAIR: Yes, and the witness was doing so, but then the witness was also addressing part of it, which I will allow her to do. Ms Lawson, you have the call.

Ms LAWSON: My understanding is that there is a requirement in there for people to have training—

The Hon. GREG DONNELLY: Whereabouts in the—

The CHAIR: Order! Mr Donnelly, please allow the witness to—

The Hon. GREG DONNELLY: Okay, sure.

Ms LAWSON: —and I would suggest that they are incorrect. I am happy to take it on notice and I will come back to you about it, but that is my understanding and I will come back to you with the reference. But I would suggest that you also need to speak to the geriatricians because I think they are wrong in what they have said in their submission.

The Hon. GREG DONNELLY: I guess it is a matter of fact what is in the legislation. Either the legislation, that is the bill—

Ms LAWSON: I think it is a pretty important fact at this point, given what you are asking.

The Hon. GREG DONNELLY: Most certainly so. That is why I am pressing it. I am talking about an enforceable requirement, not some training that they may receive as part of the rolling out of the VAD procedure in New South Wales.

The Hon. TREVOR KHAN: But that is precisely what she is saying.

The Hon. GREG DONNELLY: What?

The Hon. TREVOR KHAN: That it is a requirement of the rollout that they receive training.

The Hon. GREG DONNELLY: No, this is—

The CHAIR: Mr Deputy Chair—

The Hon. GREG DONNELLY: Anyway, they are taking it on notice.

The CHAIR: It has been taken on notice.

The Hon. ANTHONY D'ADAM: I was going to cover the issue of burden, but Greg has obviously traversed a lot of that ground already.

The Hon. GREG DONNELLY: I have just started actually.

The Hon. ANTHONY D'ADAM: I will ask about the issue of the experience of palliative care of older citizens in New South Wales and your view about this argument that if we improve palliative care then the need for VAD disappears. Perhaps I would just open that to the panel.

Ms APPLEBY: For the majority of cases, palliative care does do the job and helps people in those final stages of life and does manage their pain quite well, but there will always be situations where someone has an illness where they do not respond to the painkillers. A family friend had pancreatic cancer recently and could not take morphine and was in unbearable pain, and that is how she passed away unfortunately. I think in the best case scenario, yes, palliative care is a really important key part of the dying process but it will not alleviate everyone's suffering, unfortunately.

Ms BAKER: It is also a matter of personal choice. Do you want to go into palliative care and be subjected to whatever happens there or do you want to the opportunity to finish it now, die at your own time in your own place? That is a matter of choice. That is dying with dignity. I hate to keep using that title, but it gives you the dignity of not having to know that you are wearing a nappy or that you are unable to stand—all of the things that are so embarrassing. The things that impacted on my mother so badly was that she lost the capacity and she could not bear the fact that she was then as she was as a baby, with no self-agency, no capacity to determine for herself, and she would rather have gone sooner than later in that situation. I know that my two friends when they get to the stage where they will be offered palliative care or some way of shuffling off, they will take the shuffle because that then allows them the agency and the control. Old people are treated like we are vulnerable old duffers, but we are strong, articulate, active people who have an illness that is going to kill them and that is going to kill them painfully. All of that other stuff does not go away.

The CHAIR: Ms Baker, I think it is fair to say nobody is going to accuse you of that. This question is to all of you. We know that opinion polls and opinion group surveys and the like show that voluntary assisted dying has an approval of around about 80 per cent of the population, give or take plus or minus 5 per cent or 10 per cent. Having sat through now almost three days of this inquiry, I do not know how many of the average people on the street have really thought about their death and what it would mean, yet we still see this high level of approval for VAD. I guess I am asking myself the question why would that be, given that they have not thought about the horrible deaths that we have heard about or the potential for abuse? Is it because people are scared of dying in pain or in agony or, as Ms Baker just indicated, the loss of faculty and dignity? With the members that you have spoken to in your organisations, is that partly what it is, that we want the ability to not die in pain and to die with a level of dignity attached?

Ms WRIGHT: I do not know that there are people who have not thought about this. They have had mothers and fathers and grandfathers die in the most horrible conditions, and even if they have not thought about it deeply, when asked a question, they will think, "That is the trigger." It is kind of like, "Yes, I never want to do that. I do not want to do that." Just because somebody is frail does not mean that they do not have capacity, that they do not have the right to choose, that they do not have the right to die with dignity. Just because you are frail does not take away all of your life and what you have lived and where you are at. Frail is just an annoying word to be honest.

Ms BAKER: I think that people are more afraid of being forced to live in agony and in inhumane and debilitating circumstances than they are of death itself. We have got to the stage—I look around the room; most of us have got less of it left then we had to start with.

The Hon. TREVOR KHAN: Yep!

Ms BAKER: I have got a lot less left. If I am looking at the—what is it—was it fourscore and 10 or threescore and 10 or something?

The Hon. GREG DONNELLY: It is threescore and 10.

Ms BAKER: Well, I am already one over, so that is one foot in. I am more terrified—

The Hon. GREG DONNELLY: I hope not.

The CHAIR: It would be a toe at most, Ms Baker.

Ms BAKER: You have got no idea what it is like to be 71, I can tell you.

The Hon. GREG DONNELLY: I am not that far behind.

Ms BAKER: It is not being forced to stay alive and be used as—to feel like you are an experiment, being prodded and poked and filled up and moved around and shuffled about. I would rather die than go through that dehumanisation. I think that most people who you talk to are in the same boat. They are not afraid of dying; they are afraid of being forced to live in a way that they do not want to.

The CHAIR: I note that it is four o'clock and we have hit the end of this session. For any questions that you have taken on notice, the secretariat will be in contact with you to arrange the tabling of those. I would like to say thank you to each and every one of you for making your submissions and for making yourself available today.

(The witnesses withdrew.)

CAMERON McLAREN, Private individual, before the Committee via videoconference, affirmed and examined

GREG MEWETT, Palliative Care Physician, Grampians Regional Palliative Care Team, Ballarat Health Services, before the Committee via videoconference, affirmed and examined

CHARLIE CORKE, Acting Chair, Voluntary Assisted Dying Review Board, Victoria, before the Committee via videoconference, affirmed and examined

The CHAIR: Welcome to our next session. Now is the opportunity to provide opening statements. Dr McLaren, I invite you to make an opening statement.

Dr McLAREN: Thank you, Mr Chair. I am a medical oncologist in Victoria. As part of my diagnosis to death approach to supporting patients with cancer, I provide voluntary assisted dying [VAD] assessments. I completed my VAD training on 19 June 2019, the day that the legislation became active in Victoria. I underwent the training for two reasons: I did not want a patient for whom I had cared throughout their journey with cancer to have to seek external providers that they chose to pursue this option; secondly, having been educated in medicine with a strong focus on patient-centred care, I felt that my opinion on VAD was irrelevant to whether my patients should be able to access it. I naively expected that many of my colleagues would do the same. Through a combination of my willingness to support patient choice, the requirement in Victoria for one VAD-assessing doctor to be a specialist in the area of the patient's illness, the majority of patients [inaudible] an uptake of VAD amongst my colleagues, I have to date been involved in 176 cases—

The CHAIR: Dr McLaren, apologies. Our system just had a slight dropout. I do not know if it is your connection or ours. Could you try again and perhaps go from the start of that paragraph of your opening statement?

Dr McLAREN: Thank you, Mr Chair. Can you hear me okay now?

The CHAIR: We have got you, thank you.

Dr McLAREN: Through a combination of my willingness to support patient choice, the requirement in Victoria for one VAD-assessing doctor to be a specialist in the area of a patient's illness, the majority of patients applying for VAD having a malignant diagnosis and the low uptake of VAD amongst my colleagues, I have to date been involved in 176 cases of application for VAD, which accounts for over 20 per cent of the total number of VAD applicants to date. Seventy of these cases have resulted in the administration of VAD medication by or to the patient, and I have been present at over 50 of these, including providing intravenous practitioner administration on 17 occasions.

Along with Dr Mewett, I am one of the clinical moderators of our State-based VAD community practice, and I have founded an organisation to educate and support other practitioners as we work together to improve the quality of assessment provision and patient care in this field. I am undertaking a PhD into the effect of VAD on the grief and bereavement experience in close contacts of patients who elect to pursue VAD, as anecdotally I have witnessed a notably better acute grief response to VAD deaths than the many others that I have experienced. As part of this I have coordinated an analysis of a case series of 344 patients who applied for [inaudible] of the legislation. I submitted both my PowerPoint slides and the video recordings of my presentation of this data at a national oncology conference to the Committee for your review.

Through my work in Victoria I have had to become intimately familiar with the Victorian VAD Act and the intersection between law—an often black-and-white field—and medicine, which I often describe as a highly scientific art form. There are many aspects of the Victorian Act which are simply not working. I am looking forward to the five-year review to highlight several areas to target for amendments. Some may cry "slippery slope" when I mention this, others may see it as it truly is: as the application of the scientific method in observing outcomes and adapting the practice. I hope that I can provide some insight into how I assess capacity, coercion and the conversations I have with patients and their families when they choose to explore VAD as an end-of-life care option.

When I meet someone for a VAD assessment, I start by talking about everything but VAD: "Where were you born? Tell me about your parents. Tell me about your family. What did you do for work? What are you proud of? What do you still enjoy?" These responses start to give structure to the psychosocial framework in which this person sits. Then I ask them around their illness: "When were you diagnosed? What treatments have you had? Are you having any more treatments? What has been explained to you about further treatments? What are your expectations on your prognosis?" Through my work in VAD I have stopped asking patients about their pain and their nausea. I now ask patients, "Tell me about your suffering. When did you need palliative care?" If they have not, I explore that further and encourage them to allow me to refer them. Only then do I move on to VAD specifically: "What do you understand about VAD? Why does VAD appeal to you?" These responses often convey much with regard to what they have been through and their insight into their own condition, which goes a long way towards establishing capacity.

Next: "What was it like when you first talked about this with your family? What would your family think if you changed your mind and you didn't want VAD?" Responses, including non-verbal, that suggest hesitation or indicate something under the surface are then explored as well. Often I excuse family members from the room and I ask the patient directly, "Does anyone want you to go through with VAD?" I ask directly about their will and who might benefit and if they feel anyone is after their estate. I tell them that I will make up a reason that they are ineligible, this is not something that they truly want to do. I often call GPs and other specialists, other family members, and ask them if they have any concerns.

In my 176 cases I had but one case where concerns of coercion were raised. It took four separate home visits in one week to explore this adequately and it turned out the patient was educated about the existence of VAD by their family member, but as soon as they heard about it knew that they wanted it. When I contrast this with my clinical experience in oncology, I would estimate every two to three weeks someone makes the decision to receive more chemotherapy at least in part for their family. I hope this gives some insight into the VAD assessments as in being in no way a tick-box exercise and what I hope to improve in the future through my organisation. Thank you.

The CHAIR: Thank you very much for that, Dr McLaren. On the assumption that was your written opening statement—and this goes for the other witnesses as well—it may assist us if you are able to send that through to our secretariat. Also it assists Hansard in the transcribing. If you would not mind doing that, that would be much appreciated. Dr Mewett, can I invite you to make an opening statement please?

Dr MEWETT: I have not got a written pre-prepared statement. I am going to spend a couple of minutes explaining what I do and what my involvement with VAD has been and hopefully allow plenty of time for questions from the Committee about our experience here in Victoria. I was a GP in central Victoria in a rural and regional setting for 22 years; the latter 15 of those years I was very involved in palliative care as a GP and supporting the Long Gully Palliative Care Service in our Bendigo region in Victoria there. I then left general practice and retrained as a palliative care specialist in Melbourne and have been now a specialist palliative care physician in Ballarat for the last 14 years. I have been a palliative care specialist now for 15 years.

I was asked to be a member of the Voluntary Assisted Dying Implementation Taskforce, which was appointed by the State Minister for Health in Victoria to oversee the introduction of VAD legislation into practice. I am a conscientious provider. You have probably heard a lot about conscientious objectors, but I am a conscientious provider of voluntary assisted dying to those patients who are deemed eligible under the legislation, and I combine this with my usual palliative care day to day in my palliative care practice. I have been involved with 42 patients—a lot less than Dr McLaren. I work in a smaller area, but 42 patients I have been involved in their assessment, mainly as the coordinating practitioner, the practitioner that does a lot of the [inaudible], if you like, and supports the patient through the process.

Fifteen of these patients have died before the completion of the VAD process, which therein lies another story. Nineteen of the deaths have been by self-administration; most of those, 13, have been in private homes, four of them have been at our local palliative care unit, one in a regional hospital and one in a nursing home. I have not been involved in any practice which has administered voluntary assisted dying, but I am certainly prepared to do so should the necessity arise. I have eight pending cases that are still yet to be determined or come to conclusion.

One of the things that I really found interesting when I was involved in VAD, when I came to this work I had a bit of a preconceived idea of what sort of people would these be that are requesting voluntary assisted dying, that they actually want to take control or, I thought, to some extent maybe a little bit flippantly, I thought maybe they are control freaks, that they are people who really want to take absolute control of everything over their life and this is the way they are going to remain in control here. But I have actually found it is all sorts of people. In the 42 patients I have met, they come from a wide variety of education and socio-economic backgrounds. There is often this thought that people are small "l" liberal-minded, well-educated, university-educated people. This is not the case, in my experience.

Coercion is not an issue that I have come up against and, as Dr McLaren has alluded to, I have seen many people being coerced into doing things by their family when they perhaps should not be in health care generally. The other thing that is often thrown up is cognitive impairment and depression. But once again, over the many years I have been in practice both as a GP and as a family care physician, these are things that are second nature to us. Sure, the stakes are higher in VAD requests, and it behoves us all to be more attentive to capacity assessment and to assessing whether a patient's mental health condition might be impacting on the decision-making, but I can honestly say that outside that 43, I excluded one patient on the grounds of serious mental illness, which required much further assessment and management.

I am surprised how these patients use humour in a dark and funny way in many ways that you would not expect. I have dealt with people who are close to death all of my life; patients use this and they use it as a way of coping. All of them are well supported by families and friends—that does not mean that all their families agree with what they are doing. Most of these families do not want the person to die. Coercing them and making them die, in my opinion, must be exceedingly small, and Dr McLaren has already alluded to that. These patients do not want to die, their families do not want them to die, but in fact they are [inaudible].

My final comments would be that I find this, as a palliative care doctor, patient-centred care [inaudible]. This is really focusing on patient-centredness, really listening, leaning into these people and having a really good conversation. Not all these patients go on with their VAD request; some of them will be happy to continue with other options, but this leads to very meaningful conversations near the end of life and these patients are often very grateful and their families very grateful afterwards that their wishes have been able to be honoured and acceded to. In my opinion, despite what you might have heard from some palliative colleagues, VAD sits comfortably beside palliative care in my practice, in my opinion. We are supposed to be the experts on end-of-life care, on end-of-life conversations and on ethical decision-making and assisting patients with decision-making options at the end of life, and therefore VAD is not in opposition to palliative care. Palliative care is a style of care which, near the end of life, VAD is one type of choice in that care—they are not mutually exclusive. So with that, I will conclude and pass on to the next speaker and then hopefully we will have some good questions. Thank you.

The CHAIR: Thank you very much, Dr Mewett. Associate Professor Corke, could I invite you to make an opening statement?

Associate Professor CORKE: Yes. I am Associate Professor Charlie Corke and I am here today to share the experience of the Victorian Voluntary Assisted Dying Review Board. The board is of the opinion that the Victorian Act is working, with overwhelming positive feedback from patients and families who have used the service. Our experience is documented in our reports of operation. The priority of the board is to ensure compliance with legislation. A detailed review of each and every case has identified no instance of clinical noncompliance and very few cases of administrative noncompliance.

The second role of the board is to ensure that patients have reasonable access to voluntary assisted dying and the board has identified significant issues in this regard. In many respects, greater safeguards result in more difficult access, and an appropriate balance needs to be found. In the light of these observations, I would like to submit some specific comments on your draft legislation. While some medical practitioners are conscientious objectors, the overwhelming majority are reluctant to become involved because of the additional paperwork and other impositions of the process. Undue focus on the potential for criminal liability for noncompliance has the potential to exacerbate this reluctance.

While I can appreciate the intent of the requirement in section 23, I wonder if all medical practitioners submit a first request form whenever asked about voluntary assisted dying, it could benefit from further consideration. This form includes multiple fields and I suspect compliance by practitioners may be low. Is it possible that providing resources for applicants to submit this data might more effectively satisfy this requirement? I wonder about the need and efficacy of the consultation referral form, as identified in section 34. There are existing, well-established practices for referral and this introduces a new, different and additional process. Failure to comply with this requirement is criminalised, which may further antagonise practitioners.

Should the medical practitioner need to refer for opinion in section 27, then I presume that the five days outlined in section 23 would not apply. Interpreted through a rigid lens, citizenship and permanent residency requirements can appear very insensitive and unfair. Addition of a commonsense clause could assist in this regard. I note that the Act permits discretion in relation to residents, with the board empowered to interpret "substantial connection to New South Wales", which I commend.

Medical practitioners are not noted for their comprehensive clinical record writing. The Act mandates very specific requirements for documentation in the medical record at numerous stages in the process. This requirement makes it virtually certain that noncompliance will occur with this aspect of the legislation. The implications of this merit consideration. Finally, I raise the legislative requirement that the chair and deputy chair of the review board must be lawyers—section 144. While a lawyer may well be the best person for each role, I question the need for this to be legislated. Strong medical leadership on the board may be very desirable under particular circumstances, as may skilled governance expertise or an appointment that highlights the voice of the community. Legislation regarding these positions limits options. Thank you very much.

The CHAIR: Thank you very much for that opening statement, Associate Professor Corke. I will now open for questions. I am looking around the room to see if we have got some questions from members. No doubt the Deputy Chair is ready to kick off.

The Hon. GREG DONNELLY: Sure, I will start. Thank you, gentlemen, for making yourself available today. Just for clarification, none of you have made a submission to the inquiry?

Dr MEWETT: No, I have not.

Associate Professor CORKE: No.

The Hon. GREG DONNELLY: So were you invited to participate by being sent an invitation to participate by giving oral evidence? Just so I understand.

Dr MEWETT: Yes.

Associate Professor CORKE: That is correct.

The Hon. GREG DONNELLY: So you will forward your opening statements to us so they will be incorporated as evidence? That is fine, thank you. Can I start with this statement and perhaps, specifically, with you, Associate Professor Corke. We have received a number of submissions to this inquiry, in terms of substantive ones in terms of material content, probably around 110 or thereabouts. With respect to a number of those submissions, and we will include organisations like The Law Society of New South Wales or the New South Wales Bar Association—I will just use those as two examples, but this equally applies to a number of submissions. They express concerns with aspects of the bill, provisions within the bill, and actually propose amendments to the bill to deal with these, as they see potential gaps or deficiencies or shortcomings of the bill, perhaps around how the language is framed or, in fact, they might see a gap in the bill they think needs to be filled.

I put it to you, Associate Professor, in the last piece of your evidence that you were giving just then, in a sense you are proposing to go the other way potentially. What I mean by that is this: The proponents of the bill in New South Wales, at least as far as it has passed through the Legislative Assembly with amendments, are saying, "That's fine, we're happy with that. In fact, we want it to pass through the Legislative Council with no amendments." So that is what is being said by the proponents of the bill here in New South Wales, and you are coming forth with proposals to, dare I say, either remove or dilute certain provisions, which, I have to say, have been considered as safeguards—

The CHAIR: Mr Donnelly, I am going to have to rule—

The Hon. GREG DONNELLY: No, I am setting the context. My question is that one person's safeguards are another person's set of obstacles, as they judge them to be. So it is a matter of perspective, and I respect the fact that you are bringing your perspective to it, but there are also other perspectives that go beyond the medical perspective. I would like you to comment on that, Associate Professor.

Associate Professor CORKE: I accept your point that safeguards—and in my submission I made it clear that safeguards and access are, in a way, contradictory: that the more safeguards you have, the more you make it very difficult to access the right to access voluntary assisted dying. Where that sweet point is is a matter of judgement. I would say, in terms of some of the issues that we are dealing with in Victoria, a number of these so-called safeguards that were put into the Act make it very difficult for patients to have timely access to the Act and do not appear to add perhaps to the actual safety. So for somebody who does not actually perhaps see the value in patient choice and in this Act, then perhaps the biggest safeguard is never letting anybody get through and not having access to it. So this is a balance and a problem. I am not sure that because particular bodies that are perhaps not involved in the actual process of medicine making submissions—they might have good intent but they may make the actual delivery of the service very frustrating for patients to the extent that the patients die without accessing something that is legal that they wish to access. I am not sure that is a good outcome for anybody.

The Hon. GREG DONNELLY: But can I just follow on, Associate Professor. Just take today, for example. We have had appearances before the Committee by the Australian Medical Association.

The CHAIR: Not today.

The Hon. SCOTT FARLOW: Yes, we have, this morning.

The Hon. GREG DONNELLY: This morning—the AMA (NSW).

The Hon. SCOTT FARLOW: It was the first witness.

The CHAIR: Sorry, yes.

The Hon. GREG DONNELLY: The AMA New South Wales branch and the Royal Australian and New Zealand College of Psychiatrists. I presume you have read both of their submissions to this inquiry?

Associate Professor CORKE: I have not.

The Hon. GREG DONNELLY: Well, may I suggest to you—and I appreciate your answer that you have not read them—both of those submissions are replete with commentary and, in certain aspects, specific proposed amendments to deal with aspects that they see as potential concerns with the bill. So I put it to you that these are not organisations that are anti-VAD. We are talking about the principal trade union that represents doctors in the State of New South Wales and the college that represents psychiatrists in Australia. That is what they are saying, so how do you actually square that—and I say this in a most respectful way—with what might be a relatively small group of doctors involved in VAD who are arguing the case that these obstacles need to be pulled down or removed because they are safeguards?

Associate Professor CORKE: I think I can answer you in two ways. Firstly, I am giving evidence to assist you. I am not sure that I am required to read all of your submissions to your inquiry. It is your inquiry and I am happy to help.

The Hon. GREG DONNELLY: I just simply make the point. These are medical colleges and—

Associate Professor CORKE: Yes, if I can answer your question, the AMA in Victoria was not supportive of the Act in Victoria. The AMA is a body and is entitled to their view. They are perhaps a body—you did say that they were the medical trade union.

The Hon. GREG DONNELLY: Yes, I used that term deliberately.

The Hon. SCOTT FARLOW: I think they used that term this morning or the Royal Australian College of General Practitioners did.

Associate Professor CORKE: Therefore, it is perhaps not a surprise that they might be taking the view of the doctors, rather than the view of the patient. I note that Dr McLaren and Dr Mewett both talked of patient-centred care. Really, the way in which we deliver health care can be considered as patient-centred care or medical-centred care or perhaps as legally-centred care or religious-centred care. There is a whole load of different ways we can look at the way we deliver care. But, fundamentally, I think patients are wanting patient-centred care rather than any of those other options.

The Hon. GREG DONNELLY: May I put it to you—

Associate Professor CORKE: The fact that a medical body has a view I do not think is an overwhelming—of course it is something for you to consider, but I do not think it is an overwhelming surprise or an overwhelming opinion.

The CHAIR: Deputy Chair, we have only 15 minutes left. I know the Hon. Anthony D'Adam has a question.

The Hon. TREVOR KHAN: I think the witness still has something else to say.

The CHAIR: Associate Professor Corke, did you want to elucidate on that?

Associate Professor CORKE: My role is in oversight of the system, and I am giving you information about how we are doing that. I think these questions would be better put to Greg and Cam, who are more clinically focused.

The CHAIR: Unfortunately we have only a limited time with you. The Hon. Anthony D'Adam has sought to ask a question. If you feel there is something else you would like to address to the Committee, noting you have not put a submission in—

The Hon. TREVOR KHAN: I would like to ask a question after the Hon. Anthony D'Adam for Dr Cameron McLaren and Dr Greg Mewett to comment on the Hon. Greg Donnelly's question.

The Hon. GREG DONNELLY: My other question is about the geriatricians.

The CHAIR: We will not descend into argument this afternoon. The Hon. Anthony D'Adam has the call.

The Hon. ANTHONY D'ADAM: Dr McLaren and Dr Mewett, both of you have touched on access issues and the capacity limitations of the system in Victoria because of the uptake of medical professionals entering into the system and getting certified and trained. I want to ask about the extent or whether there is a backlog in terms of people trying to access the system. I know, Dr Mewett, you have mentioned that a number of your patients who had been applicants had died before they were able to complete the process. Is that as a result of the I suppose choke points in the system rather than as a result of the capacity?

Dr MEWETT: I think there is a range of reasons why people do not make it through the process. One can be some of the bureaucratic impediments that have been mentioned already, for example, proving your citizenship or proving you changed your name when you got married. There is a number of requirements that take time to set up. But also there are patients who clearly deteriorate more quickly than expected and will lose capacity or die prior to having got access to voluntary assisted dying. A couple of other things—maybe we will come back to Mr Donnelly's question later.

From my point of view, we have a lot of discussions with people who want access and they repeatedly have to request access to VAD. They do not have a right to die. People often talk about this right to VAD. They have a right to ask to be assessed for VAD. They have a right to ask a doctor who is trained or someone to talk to them about VAD, but they do not have a right to die. That is pejorative and it is misleading, and I have heard that many times. But these patients have a right to be assessed and we take it seriously. Some of these patients will not endure with their request and others will continue, but some of them will not make it through the process. Dr McLaren, do you have some comments on that?

Dr McLAREN: Yes, thank you, Dr Mewett. If I may, just to follow on from the previous points, I think not everything in this legislation is a safeguard. For example, the requirements for doctors to return first request notices within a period of time after receiving them, that is in no way a safeguard and does not protect the patient or the access. That is to improve the access by making sure doctors do not delay the process and that the board gets the adequate information. So not everything in the legislation is a safeguard and, therefore, not all suggestions by Associate Professor Corke were about removing safeguards. The second point I would make is that not everything that is intended to be a safeguard functions as a safeguard.

In our case series of 344 patients, we saw 114 patients die during the process of application, and 112 of those patients were due to death during the application process, with the median time of death of about 20 days. So if the process is taking three weeks or longer, there is a significant attrition rate. The greatest step of attrition along the process, which you will be able to have a look at in one of my presentations I included in the submission emailed this morning that hopefully will be distributed, is between the consulting medical assessment and the written declaration final request and contact person appointment. That is the point in time when our nine-day cooling off period is active. Not only in our case series but also in the VAD review board report, we have not seen a patient withdraw from the process due to preference within that nine-day period. So one may question whether that intended safeguard is actually functioning as a safeguard or whether it is functioning as a barrier.

The Hon. ANTHONY D'ADAM: I am happy to hand to the Hon. Trevor Khan.

The Hon. TREVOR KHAN: Dr McLaren, I suppose I want some clarification in terms of the timing of people making the applications. If I took your last answer, people are making it very late in the journey, if I can describe it that way. We have talked about time frames of a person being diagnosed as having an illness that will essentially kill them within six months or 12 months in terms of the subcategory. That time frame seems to allow a lot of time in which the application can be made. But do I take it that, in fact, patients are doing it much later after that diagnosis in which to make the application for the scheme?

Dr McLAREN: Absolutely, and this really speaks to our ability to prognosticate accurately and also specifically the non-linear behaviour of prognoses. Some of my patients may have a prognosis of many months and then in the space of one day when they have had a CT scan showing that their cancer has progressed their prognosis is now four to six weeks. So it is not a linear regression of a predicted prognosis by any means; things change very quickly. And then people do not want to die, they do not want to think about dying, they do not want to think about how they are going to die. That is just human. But then when they are faced with something like that, a short prognosis, they suddenly think, "Well, I need to get this organised", and they scramble to get it organised in time.

I think in terms of my cases that contribute to those 344 cases—because they are not all of mine—I have functioned for the patient navigators in the State as a practitioner. We will see patients within—I mean, I am going tonight at seven o'clock to see one patient and I am going on Wednesday night to see another patient at six o'clock in the evening, and this is because they cannot attend rooms. Often they are bed bound and these are the patients with particularly short prognoses. So I do feel like I have seen a skewed proportion of that of VAD applicants, and then I see the very unwell patients who need an experienced VAD assessor to make sure there are no administrative problems along the way, or as few administrative problems along the way for their application.

The Hon. TREVOR KHAN: In terms of your patient set, if I can describe it, I think you had only one patient who was in a nursing home. Is that correct?

Dr McLAREN: I believe that was Dr Mewett's patient.

The Hon. TREVOR KHAN: Sorry.

Dr MEWETT: Mr Khan, I had one patient who self-administered her VAD medication in a nursing home. I have a small series of patients—I was just giving a flavour that most of our patients wish to take their medication at home, but there are some people for whom the nursing home is their home and that is where they elect to take their medication.

The Hon. TREVOR KHAN: Right. I think it is fair to say that we have received a not inconsiderable amount of evidence from the religiously based nursing home operators with regards to a provision of the bill that would require nursing homes to accommodate the taking of the substance in the context of the nursing home. I wonder if you have a view as to whether that provision is a necessary provision, taking into account your evidence with regards to numbers.

Dr McLAREN: I certainly do, particularly as my perspective comes not from—my personal perspective is that an institution is not sentient and therefore if they have an objection it is questionable in my mind. But I know that that is not what everyone's perspective is.

The Hon. GREG DONNELLY: A corporation.

Dr McLAREN: A corporation. So what I feel is that my perspective lies with the staff, particularly the nurses who care and who are looking after those patients. These people who are supporting this process, or this patient through this process, need to be able to individualise their involvement. People talk about forcing institutions and forcing staff to be complicit in this act, but when you have an institution that conscientiously objects you are also precluding those patients from conscientious involvement. That in my mind is a greater risk factor for issues such as moral injury of death since the staff are exposed to situations that they find ethically conflicting and are having to act in one way that is not in accordance with their personal ethical framework. So, to me, that is a much greater risk for those individual nurses and carers and that is why I prioritise the individualisation of involvement of staff and also an individual right of access of the patients or people who are residents in those nursing homes.

I think, again, talking about a patient-centred perspective is that, you know, what if they would like to take their medication there? Then that is fine. I have heard concerns raised about people who talk about, "What about the resident next door?" What struck me about that argument is that I do not understand why the resident next door is privy to the information of that resident and what business it is of theirs. I have issues with confidentiality in that case. There is no reason why someone next door needs to be aware of what is going on. So I feel the risk of harm is much less when individualisation is allowed.

The Hon. GREG DONNELLY: Can I just ask you this: Are we to take from what you just said that, to use the vernacular, if Granny Smith in a nursing home is at the end of life, she just, in effect—and she has people around her in the nursing home, her community, her network of friends—disappears, so to speak? She dies. It is your evidence that people would not necessarily know that she has ended her life with VAD? Are you seriously saying that?

Dr McLAREN: Yes, I am. That happens every day in nursing homes. That is where people die and people disappear every day in nursing homes.

The Hon. GREG DONNELLY: No, no. That is not what I said.

Dr McLAREN: It is a regular occurrence.

The Hon. TREVOR KHAN: It's God's waiting room.

The Hon. GREG DONNELLY: No, no.

The Hon. TREVOR KHAN: The room has suddenly cleared, Greg.

The Hon. GREG DONNELLY: No, no. I have been to nursing homes before as well. I am talking about the circumstances around the person's death. What we are talking about is a person committing suicide or being euthanised. People do not like this language and it has been contested over the course of today.

Dr McLAREN: Yes, and we do not prolong that.

The Hon. GREG DONNELLY: But the point I am making is that, if I understand what you are saying, the implications are there is not, and ought not be considered to be, a surprise that there actually is not an effect on other people. This is just something that happens—that people would be euthanised or commit assisted suicide. Is that your evidence?

Dr McLAREN: I am sorry, Mr Donnelly. People do die in nursing homes and—

The Hon. GREG DONNELLY: I know that.

The Hon. TREVOR KHAN: Let him finish.

Dr MEWETT: They die in palliative care units as well—

The Hon. GREG DONNELLY: [Disorder].

Dr McLAREN: In actuality, it precludes the disclosure of the terms of that death to any other individual, so it is not the business of the person next door what happened to that patient, other than that they passed away.

The Hon. GREG DONNELLY: I gather you have read the research overseas—and there is a fair bit of it—of the impact on residents of nursing home facilities whereby assisted suicide or euthanasia or VAD is introduced and that impacts on the residents of a nursing home. You would be familiar with that research, wouldn't you?

Dr McLAREN: Yes, I am.

The Hon. GREG DONNELLY: And the position is that there in fact is quite a serious effect on the mental wellbeing of people in those situations, isn't it? That is the evidence, isn't it?

Dr McLAREN: I think that evidence is quite dubious in how it has been conducted, Mr Donnelly.

The Hon. GREG DONNELLY: Okay. That is what we have come down to.

The CHAIR: Order!

The Hon. GREG DONNELLY: Okay.

The CHAIR: I thank the witnesses very much for appearing today and for giving your time and sharing your experiences with us. Unfortunately, we have run out of time. For the questions that you have taken on notice, the secretariat will be in contact with you to arrange the tabling of those answers. Again, I thank you very much.

(The witnesses withdrew.)

MICHAEL STEAD, Bishop, Anglican Church Diocese of South Sydney, sworn and examined

The CHAIR: Thank you very much, Bishop Stead. Could I trouble you to make an opening statement, please?

Bishop STEAD: I would be delighted to do so. As I said, I am the Anglican Bishop of South Sydney. Today I am speaking on behalf of the Anglican Church in the Diocese of Sydney. I do thank you for the opportunity to speak to this inquiry about the provisions of the Voluntary Assisted Dying Bill. The legal adage that hard cases make bad law applies to this voluntary assisted dying legislation. It is legislation for those in extremis—for the terminally ill, who are experiencing intolerable suffering. Our hearts rightly respond with compassion when we see others in distress and the reflex is to want to do something to ease or take away that suffering. That is perfectly understandable.

However, out of that reflex has come this particular legislation, the impact of which cannot be limited to those for whom it is primarily intended. This legislation would be better if voluntary assisted dying could only be accessed after a person had had the benefit of high quality palliative care and out of that had come to the conclusion that the palliative care could not reduce pain to a tolerable level; and furthermore that it was, if we could be sure that those who choose to bring their lives to an end were not acting under any kind of external influence, whose mental faculties were in no way impaired and who were not making a decision in a depressive state. The problem is of course that the legislation cannot guarantee any of those things and therefore will impact more people than those for whom it is intended.

Our submission proposes a number of amendments to protect four classes of vulnerable people from the unintended consequences of the bill. They are those with limited or no access to high quality palliative care, older Australians who might be subject to manipulation by unscrupulous family members, those who are subject to depression or other mental illnesses, and those who are living in residential aged care. I am aware that a number of amendments have been made to the bill since we tabled our submission and at a number of levels, at least in three of those four cases, I am pleased to see that there have been some amendments that go some small way to addressing the concerns that we have raised in each case.

The very limited nature of these amendments signals not only the problem but also that not enough steps have been taken. I note that—I am happy to take specific questions on each of these topics—there have been minor amendments in the definitions of section 4 to include high-quality palliative care and medical care but not the other things that we have suggested and that there have been some clarifications by Minister Stokes around the issue of manipulation and the requirement to give statements about pressure and duress, but again they do not go far enough. There have been some clarifications in relation to the eligibility criteria around dementia, but there is still no requirement of an objective psychological assessment as we have recommended, and there have been no amendments around the issues relating to residential aged care. Obviously I realise my opening statement is limited but I would be very happy to take particular questions around those areas as to why I think the accepted amendments do not go far enough.

Let me finish my opening statement by saying—and just to be clear—that even with those amendments I would still have in-principle reasons for opposing the bill, but it would change from a bill that I would personally not recommend and counsel people against or something that I think is in principle bad for our society. So I am proposing these amendments because, if we are going to have a bill, it has got to be something that will work long term for our society. I am concerned about the long-term impacts of this bill and what it says to people who have diminished capacity and what it says about people who already feel like they are a burden and might quite reasonably decide that they want to take their life, not because of intolerable pain but because they do not want to be a burden to their family.

I am concerned about what it means that the definition of what compassion looks like. I am concerned because of what it says about an apparent affirmation of a right to die—I do not believe there is a right to die; I am happy to take questions on that. But this bill is taking us a step in that direction and, having taken that step, it inevitably leads to wider questions about when and where we will offer State-sanctioned support in the right to be killed, because that is what this legislation is providing. So for those public policy reasons I am actually opposed to the bill in principle. But if we have to have a bill then it needs to be one that safeguards the vulnerable. Thank you for the opportunity to make that opening statement.

The Hon. SCOTT FARLOW: Bishop Stead, in your opening statement there, you mentioned that you do not believe in the right to die. I take it you believe in the right to life. Do you want to maybe expand upon why you believe there is a right to life but not necessarily a right to die?

Bishop STEAD: What I do mean is that it is not for society to support an individual's determination that they have the right to end their own life. I am not saying we should criminalise suicide. People can choose to suicide and there is nothing we can do to stop them but as a society we should be doing everything we can to counsel people against that and, therefore, we should prevent suicide to whatever extent we possibly can. Therefore as a State there should not be, as a general rule, a State-sanctioned right to be killed—in other words, "I want to die and the State has to support me in that right and provide me with the medical support to do so." If that is the basis for this legislation, then we must not have this legislation because there is no way that you can stop that at the point of the terminally ill.

A perfectly healthy 41-year-old who is feeling depressed and feels that there is nothing left to live for who decides, "I want to end my life"—I do not believe that we should as a society support them in that right. We should actively prevent them to the extent that we are able to do so. If the case for euthanasia depends on an ethical right to die, then we should oppose it for that reason. I realise that is not the reason why it is being promoted but that is my fundamental objection to this bill. It is that it is actually opening the door to that very idea that an individual can decide, "Okay, I am fed up with life. I want to kill myself." And not just, "I want to do that", but, "The State should support me in doing that."

The CHAIR: Bishop, can I then ask you following on from that, if somebody elects that they want to not suffer through pain—we have heard testimony throughout the past three days that people are taking their own life in circumstances where they are facing, or are in, intolerable pain and they do so alone with means or methods that perhaps are not as humane or as—

The Hon. TREVOR KHAN: Well, some of them are just straight-out violent.

The CHAIR: Yes. And so, while I accept your position that we should not do this because of a number of reasons which you have articulated, the reality is that we know that people are doing it.

Bishop STEAD: I perhaps have not made my point clearly enough. I am saying the philosophical underpinning must not be because we believe individuals have a right to die. If the reason we are acting is we believe an individual is in intolerable suffering and it is out of compassion to limit that suffering, that is very different to the autonomous individual deciding I can end my life at any time I choose.

The CHAIR: But that is in so many cases—which the testimony has been over the last three days—the position with which the bill is being put forward.

Bishop STEAD: And I am saying that is a terrible philosophical basis because if that is the reason why we are approving this bill then there is no reason why we should not apply it to the 21-year-old who suffers from depression. Why shouldn't we allow them their autonomy? They have chosen that they want out and I am saying as a society we have never done that. We have actually said to the 21-year-old who says I want to die, "We want to help you."

The CHAIR: I feel like we are going down a very huge philosophical discussion but there are marked differences in that this bill is related to people with a terminal illness who are perhaps—whereas the 21-year-old may elect to do it through a number of means because they have the faculties and ability and movement and the like. We are talking about people who are perhaps terminally ill, may be bedridden, in intolerable, insufferable pain.

The Hon. TREVOR KHAN: Not perhaps—the bill is only in the event of a terminal illness.

The Hon. ANTHONY D'ADAM: They are terminally ill. It only applies to people who are going to die.

The CHAIR: That is what I mean. So I think there are some marked differences between the two people that you are drawing parallels to. And I guess you are drawing the parallel that this is a slippery slope.

The Hon. GREG DONNELLY: Point of order: That is putting words in his mouth.

Bishop STEAD: I am not actually making a "slippery slope" argument; I am actually saying it is the philosophical underpinning. So if you say the reason for the bill is because we are addressing the terminally ill—and I understand that is exactly what the bill is saying—that could be morally and philosophically justified. I am not persuaded by it but I can see the justification there. What I am saying is we should not pass the bill if the only justification is based on individual autonomy and a right to die.

The Hon. TREVOR KHAN: I think that is fair. You got me on that one.

The Hon. ANTHONY D'ADAM: But that is not what is proposed.

The Hon. SCOTT FARLOW: Ambitiously, I might just continue in terms of some of the substantive issues you have raised with respect to the bill as well. You mentioned in your opening address that you believed that the amendments moved with respect to duress by Minister Stokes in the Legislative Assembly did not go far enough. Is there any substantive position you want put before the Committee as to what could be further amendments to address your concerns in that regard?

Bishop STEAD: The amendments put by Minister Stokes and passed were effectively notification provisions. They did not change the definition of pressure or duress other than adding a clarification that elder abuse could be an example of that but that is already contained within the definition because the word "abuse" is there.

The Hon. SCOTT FARLOW: So this effectively goes to your modification that you propose with respect to the definition in schedule 1, is that correct?

Bishop STEAD: That is correct because there will be lots of activities that will occur in families behind closed doors that will not amount to pressure or duress understood legally but nonetheless will be manipulative and that are designed to induce elderly, frail relatives to exit more quickly than they otherwise might have chosen and I am saying we need to go wider than that.

The Hon. TREVOR KHAN: Can I ask a follow-up question? We just heard, Bishop, from the last witnesses, and it is something that had troubled me. The assumption that seems to be made with regards to coercion and duress is that the coercion and duress is all aimed one way—that is, coercion and duress or coercion in some sense for a patient, who is dying within a relatively short period of time, to end their life even quicker. What I want to suggest to you is that family members may in fact be coercing the patient actually not to end their life, and nobody seems to worry about the fact that the patient may have been directed in a course of conduct that the patient actively does not wish to pursue—that is, to stay alive. Do you worry about that prospect? If not, why not?

Bishop STEAD: In my profession as a minister I visit palliative care units and nursing homes on a very frequent basis. Over and over again I speak to older people who say, "I do not want to be a burden," and, "I wish I could go home," and these are Christian people. We are not afraid of dying.

The Hon. TREVOR KHAN: That is not only a comment that is made by Christian people. It is made by a lot of elderly people.

Bishop STEAD: That is right. Because it has never been a choice that people have had to make at this point in time, I am not aware of any circumstances of the family saying—the only coercion if there is that is family members saying to their parents, "No, you are not a burden. This is not a burden. This is an act of love as we come in and visit you and we are not burdened." They need the reassurance to know that they are loved and this is how their family will show their love.

The Hon. TREVOR KHAN: Bishop, let me just suggest to you that the evidence we received from one of the last witnesses was about patients who are effectively coerced into continuing with a course of chemotherapy which the patient may not wish to persist with. I can think of a number of other circumstances. I will suggest another one: patients who choose to give up eating because they want to die and are then pressured by the family to eat. I know that is an extremist one, but the coercion does not have to be one way. Indeed, if you talk about subtle coercion such as that, it may be for the best of intentions—that is in a sense if we talk, as some of our submissions have, in terms of transference. What the family member thinks is the right thing to do may be quite different from what the patient wishes to do or the dying patient. But I do not think you can necessarily say it is all bad.

Bishop STEAD: I can only speak from my experience. I have not seen any coercion going the wrong way as you would put it—

The Hon. TREVOR KHAN: Really?

Bishop STEAD: —of that kind. My follow-up point would be to say and even if there was, the consequences of that are not permanent, whereas the consequences of coercion into voluntary ending of life is irreversible. Even if there was that kind of coercion going on, it is not beyond the possibility that other medical staff can intervene and say, "Actually, there is no point continuing this hopeless treatment of chemo. It is only just making them sick." It is addressable and reversible, but the very problem with the issue that we are dealing with here is that terminating a life is terminal and it is irreversible.

The Hon. TREVOR KHAN: Of a patient who is dying. We are dealing with a class of people where there is an identifiable outcome—that is, death. The question is the quality in a sense of that death from the perspective of the patient. Is that right?

Bishop STEAD: I would put the focus on the quality of the last stages of their life rather than the quality of their death.

The Hon. TREVOR KHAN: Bishop, I do not really want to read to you parts of the transcript as I have done with other witnesses, but some of the evidence that we have received in this inquiry is that the quality of the passing has been appalling. Whether those difficult cases make good or bad law, as we have heard repeated time and time again, there are people who have very awful deaths. The question is how we as a society deal with those, and some of them are not assisted by palliative care. That is a real problem, is it not?

Bishop STEAD: A very small number of people—and I put the number at less than 2 per cent, again, not as a practitioner but as somebody who visits a lot of people in palliative care—

The Hon. TREVOR KHAN: I think we are probably going to agree with that sort of number.

Bishop STEAD: These are the people for whom palliative care cannot address the pain and for them to remain conscious—and there is still always the option of deep opiate care. In other words, they are effectively unconscious.

The Hon. TREVOR KHAN: The problem with that proposition to limit it simply to pain is that, as we heard from again other witnesses today, Mum, apart from suffering pain, really does not want to be lying in a bed in a nappy having lost essentially her own self-image of what it means to be an adult, does not want to be completely bedridden, and does not want to in so many other circumstances suffer the indignities of life that she is now confronted with. Are those not equally as important to the self-image of humanity as pain and the indignities of pain?

Bishop STEAD: This is probably the point at which we will disagree because I think as a society the thing we want to say to Mum in those circumstances is not, "Yes, Mum, you have lost all dignity of life. Let us end it," but, "Mum, no, you still have dignity, even when you have lost all bodily control. You are still a valuable human being whom we love and we care for and we respect you. We love and care for you." That is, we want to affirm the dignity of people rather than confirm their self-assessment that they have lost all dignity and that it actually goes to the very issue. I do—

The Hon. TREVOR KHAN: I do not want to personalise this in terms of my experience, but it is not a question of whether, for instance, I loved my father and sought to reinforce with him his dignity. The problem was his perception of his circumstance. What do you do about the patient who says, "This is no way to live. I do not want to lie here having to be pulled out of bed on a crane in order to change my nappy because I am just so moribund"? How do you deal with the patient's perception, not the family but the patient?

Bishop STEAD: Again, the same way that you would deal with the paraplegic or the quadriplegic who is not terminally ill but feels exactly the same way and says, "My life is not worth living." We actually need as a society to affirm them and say, "No, your ability or lack thereof is not the thing that defines you as a human being." These are the kind of public policy reasons why I oppose the legislation, because it reinforces the message that you have to be able to have dignity.

The Hon. SCOTT FARLOW: With respect to your concerns with respect to residential aged-care facilities, particularly operated by the Anglican Church—and I would have liked to have asked Anglicare and other providers this the other day, but we did not have the time—you outline a range of amendments there, and I think they speak for themselves. What has your experience been in other States where such facilities operate and the regimes that exist there under voluntary assisted dying legislation? Are there any differences and has that impacted the provision of service in those States?

Bishop STEAD: Let me preface what I am about to say by saying that Anglicare operates provincially and locally. Therefore, I can only speak for Anglicare in the Sydney diocese and I cannot actually speak for the experience of Anglicare in Victoria. My understanding is that there has not been issues in Victoria with institutions having to participate against their will. The amendments that we have proposed, and you will see that they are almost exactly the same as the ones proposed by Anglicare in their submission, are trying to strike a balance between recognising that there will be people in Anglicare residential aged care who would like to access voluntary assisted dying and at the same time we want to create an environment for the residents in those places to have a safe haven from voluntary assisted dying.

I came in at the tail end of the last hearing and I think I would come to a very different understanding of what actually goes on in residential aged care in terms of the awareness of the residents. Sometimes in the room next door, sometimes in the bed next door, they do know how each other have died. It is not just that people mysteriously disappear in the night and there is never any conversation about it. Particularly when there is going to be an at least five-day or week-long preparatory process to somebody being approved for voluntary assisted dying, it will be known that the people who live in the room next door have chosen to end their life. It will not be because the medical practitioners have disclosed it against their imposed duties of privacy; it will be because the residents themselves talk about it.

The issue I have got is that you are going to have people living in residential aged care who themselves do not want to experience voluntary assisted dying and want to be able to trust their doctors and nurses as the people who are doing their best to keep them alive whilst knowing that the very same doctors and nurses in the room next door are the ones who are administrating a lethal dose. Maybe if you are—like most of us in this room, I trust—not suffering any kind of cognitive impairment, you can make that distinction. But for many of the people who live in our aged-care facilities, things are a little bit—are less clear and they are going to not be able to make the distinction between the doctor who is caring for me and the doctor who is terminating my friend without some transference of fear. So we propose some amendments which would at least insulate all of the residents if voluntary assisted dying is not taking place on the premises, it actually means that it is one step removed. And we think that that is the appropriate balance between protecting those whose home it is to continue to live there and protecting those whose home it is who want to end their life there.

The Hon. TREVOR KHAN: At what point would you say the patient has to be removed from the home? Is it for the actual act of—

Bishop STEAD: Yes. You will see that our proposal is that the consultation process, the two doctors' visits, could occur in the facility. It would only be at the point of the administration of the lethal substance that they would be transferred to another facility.

The Hon. GREG DONNELLY: Thank you very much for coming along, Bishop. Your submission is very helpful, particularly with respect to the framing of some thoughtful amendments. The matter that starts at paragraph 16 of your submission under the heading "Prioritising Voluntary Assisted Dying Over Palliative Care"—I have three minutes and time is going to beat us. I present this to you for comment and I will follow up with supplementary questions. We know through a plethora of evidence that has been provided not just to this inquiry but to other inquiries conducted by the Parliament of New South Wales, two of which are in the Legislative Council, that there are manifest shortages and gaps in the provisions of palliative care all around New South Wales. We had evidence this morning even with respect to large metropolitan cities. That is a statement of fact.

As I understand, as with so many of the submissions that have been made and oral evidence given, this legislation is predicated around the matter of choice, people exercising free choice. But bearing in mind there have been provisions put into the legislation—particularly in the principles clause, I am talking about subclause 4 (1) (d)—about "should be provided with high-quality palliative care and treatment", this is essentially a fictitious dream we are looking at. This is not provided now. No-one is suggesting that within 18 months of the operationalisation of this law, if it passes the Legislative Council, that people around the State will have access to high-quality palliative care. Do we not run into this issue that there is a fundamental problem underpinning this debate and discussion of the bill about choice when, in fact, a person will be able to potentially get access to the pharmaceutical, or the high dosage, to commit suicide or be euthanised but cannot access palliative care? Isn't that a fundamental problem we face in New South Wales with the introduction of this legislation?

Bishop STEAD: Indeed. The first section of our submission is really predicated on that fear. Based on our understanding, New South Wales has less than half the number of palliative care beds that it needs. When you move into regional, rural and remote New South Wales, as you say, it is fictitious, the idea that people have any access to palliative care. It is no choice to tell somebody who lives in Mullumbimby, to pick somewhere I was last week, that you have the choice between high-quality palliative care but there is actually no available palliative care beds anywhere within an hour's drive. Therefore, our amendments are, in a sense, designed to highlight that. My preference is that we do not pass this bill, but if we are going to pass the bill then we need to prioritise palliative care at the same time. That is going to require the investment of something like $294 million over the next 18 months in order to get the requisite number of palliative care beds, and even then you are still going to have issues in regional, rural and remote New South Wales. So there is a fundamental problem there.

The CHAIR: Bishop Stead, thank you not only for the submission but also for making yourself available today. We have reached the end of the hearing not only for today but also for the inquiry itself. For the questions that you have taken on notice, the secretariat will be contacting you to organise their tabling. Once again, I thank you. We will draw this day and inquiry to a close.

(The witness withdrew.)

The Committee adjourned at 17: 15.